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**COUNSELLING IN  
INFLAMMATORY BOWEL DISEASE**

by

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## SUMMARY

### “Counselling in inflammatory bowel disease”

INTRODUCTION; The inflammatory bowel diseases (IBD), Crohn’s disease (CD) and ulcerative colitis (UC), affect well over 100,000 people in the United Kingdom. Health related quality of life (HRQOL) is influenced by many factors in IBD including; the nature and severity of the disease, socio-economic factors, age, psychological well-being as well as the efficacy and complications of treatment.

PILOT STUDIES; Quality of life was assessed in 140 IBD patients (70 CD/70 UC). Diarrhoea was, not surprisingly, the most commonly reported physical symptom in both CD and UC and impaired faecal continence caused great social disability, with 72% CD patients and 68% UC patients reporting urgency or incontinence. Over a third of all patients reported occupational problems associated with their disease. Anxiety, but not depression, was common in the CD group and a major source of anxiety in many cases was lack of information. Three-quarters of patients felt additional information would have enabled them to cope with their chronic illness.

It is a common perception that the provision of psychological support, such as the use of counselling skills, may alleviate many of the psychosocial problems associated with IBD, but this has not yet been proven.

HYPOTHESIS: That a nurse led counselling service improves HRQOL in IBD patients.

**STUDY GROUP/ DESIGN:** Fifty patients with CD (aged 16-64, 33 females), 50 UC patients (aged 17-60, 26 females), 50 healthy volunteers (HV, aged 17-61, 27 females) and a disease control group comprising 28 psoriatic arthritis (PS) patients (aged 22-66, 16 females) underwent structured interviews and completed a range of questionnaires measuring several facets of quality of life and psychological well-being (Hospital Anxiety and Depression Score (HAD), Attitudes and Preferences (AP), Styles and Strategies (SS) and Short-form 36 (SF36)). Patients with IBD were then randomised to receive either a counselling package or routine clinical follow-up. The counselling package consisted of disease specific information and teaching of stress management techniques, based on the "Challenge to change" programme devised by Dr. Derek Roger at the University of York. HRQOL scores were compared on entry at 6 and 12 months.

**RESULTS;** At baseline the scores for all questionnaires were within the normal range in the UC, PS, and HV groups. However CD patients recorded significantly higher anxiety scores ( $p<0.01$ ) and demonstrated significantly higher maladaptive coping mechanism scores ( $p<0.05$ ). At six months, the anxiety scores of the CD patients improved significantly ( $p<0.05$ ) as did their maladaptive coping mechanism scores ( $P<0.05$ ). There was no significant change in disease activity over this period. These improvements were maintained at twelve months.

**SUMMARY/ CONCLUSION;** Psychological morbidity is common in CD and can be quantified using validated questionnaires. Psychological morbidity

improves with basic psychological support and information provision but sophisticated stress management techniques are probably unnecessary.



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**PART ONE**

**CHAPTER ONE**

**INFLAMMATORY BOWEL DISEASE**



## **1.1 Introduction**

Crohn's disease and ulcerative colitis are idiopathic chronic bowel diseases. Although they are generally recognised as distinct clinical syndromes they are very closely related illnesses and are commonly grouped together under the term inflammatory bowel disease (IBD).

## **1.2 Incidence and prevalence**

The prevalence of Crohn's disease varies between geographical locations. It affects 30-50 per 100,000 of the population in Northern Europe, the United States of America and Australia but appears less common in other areas of the world.

Crohn's disease occurs more frequently among Caucasians than those of Asian and African origins. The incidence of Crohn's disease in British Asians is higher than that of natives from the Indian sub-continent (Fellows et al. 1990). Similarly among Afro-Caribbean's the incidence of Crohn's disease is greater in black British West Indians than in native Africans (Fellows et al. 1988).

Crohn's disease can present at any age although it most commonly develops between fifteen to thirty years of age. It occurs equally common in men and women and at least in the United kingdom is unaffected by social class (Puntis et al. 1984).

Ulcerative colitis affects 80 per 100,000 of the general population, and is as such is nearly twice as common as Crohn's disease. There are no associations with race, gender and social class. The median age of incidence lies between

fifteen and thirty years with a second peak aged between fifty five and seventy, although no age is exempt (Barton et al. 1989).

### **1.3 Aetiology and pathogenesis**

The aetiology of both Crohn's disease and ulcerative colitis remain unknown. It is still debated whether Crohn's disease and ulcerative colitis are separate diseases or whether they represent a continuous spectrum of inflammatory bowel disease (Rhodes et al. 1994).

There are many suggested predisposing factors related to the development of IBD. Many different predisposing factors for the development of IBD have been proposed, the evidence for these is mostly inconclusive. They can be divided into environmental and genetic factors. Environmental factors include decreased fibre and sugar consumption and protection from breast feeding. Calkins et al. (1986) suggest that oral contraception is associated with Crohn's disease. The mechanism for this is unclear but vascular factors may be relevant.

Studies have shown that both Crohn's disease and ulcerative colitis occur more commonly than expected by chance within families. This pattern could arise from either common, predisposing genetic factors within the family, or common environmental influences (Mayberry et al. 1980).

It has been suggested that Crohn's disease may be related in some way to Mycobacterial infection although immunological and therapeutic studies do not

show evidence of Mycobacteria infection in the majority of cases (Monson et al. 1987). Wakefield et al. (1995) identified viral particles within the vascular endothelium of affected bowel and suggested that these particles represent infection with measles virus.

The pathogenesis of the diseases is also unclear. The major hypothesis relates to abnormal immune responses and dysfunctional immune-regulation within the bowel wall (Sanderson et al. 1992). The Inflammatory Bowel Disease Study group at the Royal Free Hospital School of Medicine tested the hypothesis that the primary pathological abnormality in Crohn's disease is a defective mesenteric blood supply resulting in multifocal gastrointestinal infarction (Pounder, 1995).

Psychological factors are addressed in Chapter Three.

## **1.4 Ulcerative colitis; an overview**

### **1.4.1 Presentation**

Ulcerative colitis is an inflammatory disorder of the colonic mucosa. The disease is characterised by a chronic relapsing and remitting course. The dominant symptom in ulcerative colitis is diarrhoea, which is usually, but not always, associated with blood and / or mucous in the stool (Both et al. 1983).

The onset of ulcerative colitis is usually gradual, but it can be abrupt and there may be a previous history of episodic diarrhoea. Loose bowel movements are a

consequence of the inflamed rectum and bowel frequency is related to the severity of the disease (Rao et al. 1988).

Abdominal pain is not a prominent symptom for most patients with ulcerative colitis, but mild colicky pain or lower abdominal discomfort relieved by defaecation may be present in some patients. In severe disease, patients can present with fever, symptomatic anaemia, weight loss, malaise and lethargy. Extra-intestinal manifestations of ulcerative colitis affect 10-20% of patients these include primary sclerosing cholangitis, erythema nodosum, pyoderma gangrenosum, iritis and arthritis.

Ulcerative colitis commonly follows a chronic intermittent course, marked by long periods of quiescence interspersed with acute attacks lasting for weeks or months. The reason for these relapses, is usually unknown, although Riley et al. (1990) postulate several causative factors such as seasonality, drug ingestion and emotional stress. Emotional stress is examined in this thesis.

#### **1.4.2 Diagnosis**

Diagnosis is based upon a history of chronic bowel disorder with sigmoidoscopic appearances of granularity, friability and bleeding confirmed by histological examination of rectal biopsies. The extent of the disease is defined by colonoscopy or air contrast barium enema.

### **1.4.3 Disease severity**

Truelove and Witts (1955) devised a simple and practical system for classifying patients with ulcerative colitis into those with mild, moderately severe and severe disease based on symptoms, physical findings and laboratory tests (Table 1.1). Severe disease is defined as the passage of six or more bloody stools daily with systemic disturbances including fever, tachycardia, anaemia or an elevated erythrocyte sedimentation rate (ESR). Mild disease consists of four or less stools per day with little or no blood, the absence of systemic illness or an elevated erythrocyte sedimentation rate. Moderate disease is classified as being intermediate between mild and severe.

Table 1.1

Disease Severity in Ulcerative Colitis ( Truelove and Witts 1955)

Feature	Mild	Moderate	Severe
Motions a day	<4	4-6	>6
Rectal bleeding	Small	Moderate	Large amounts
Temperature	Apyrexial	Intermediate	>37.8c
Pulse rate	Normal	Intermediate	>90 beats a minute
Haemoglobin	>11 g/dl.	Intermediate	< 10.5 g/dl.
ESR	< 30 mm/h	Intermediate	> 30 mm/h

**1.4.4 Complications**

Acute toxic dilatation may occur in patients with a severe pancolitis. Without prompt treatment, toxic dilatation may lead to perforation and generalised peritonitis (Jalan et al. 1969). Patients with extensive colitis have an increased risk for the development of colonic cancer, although the magnitude of risk is as yet undefined (Lennard-Jones et al. 1990).

Prior to the development of cancer in ulcerative colitis, colonic biopsies may show dysplasia, and for this reason screening colonoscopy is undertaken in

patients with extensive colitis of more than ten years' duration. Systemic, extraintestinal complications include large joint arthritis, uveitis, pyoderma gangrenosum, erythema nodosum and primary sclerosing cholangitis.

## **1.5 Crohn's disease; An overview**

### **1.5.1 Presentation**

Crohn's disease is characterised by a chronic transmural granulomatous inflammation, which can affect any area of the gastrointestinal tract, often in discontinuity. There are a wide range of presenting symptoms which vary according to the site affected.

Crohn's disease most commonly affects the terminal ileum and proximal colon. Some patients have isolated small bowel or exclusively colonic involvement. Extensive colonic involvement often presents with diarrhoea, general malaise, associated with anorexia weight loss and abdominal discomfort. Crohn's colitis may be complicated by colonic perforation leading to an acute abdominal emergency (Allan et al. 1977; Cooke and Swan, 1995). A characteristic feature is that of fistula formation; between loops of bowel, bowel and bladder and bowel and vagina.

Perianal disease is present in more than two-thirds of patients with Crohn's disease, though it is often painless and asymptomatic. Perianal disease only becomes painful when there is local abscess formation or active anal fissure.

Ileal disease often presents with abdominal pain, diarrhoea and an abdominal mass. Severe symptoms with general malaise, anorexia, weight loss and peripheral oedema, together with a low serum albumin, may occur. Aphthous ulceration is a common feature of Crohn's disease, such ulceration can be extensive and painful enough to impair nutrition.

### **1.5.2 Diagnosis**

Diagnosis of Crohn's disease is based upon the clinical history, physical findings, laboratory data, endoscopic and radiological examinations. In most patients a good quality barium follow through or barium enema examination will identify the characteristic features and define the site of macroscopic disease.

### **1.5.3 Complications of Crohn's disease**

Small bowel obstruction occurring in Crohn's disease results from strictures due to fibrosis, with superimposed spasm, inflammation, or intestinal adhesions. Abscesses can form from either local perforation proximal to a stricture, a penetrating ulcer or inflammatory change in locally involved lymph nodes. This complication leads to pain with anorexia, weight loss, fluctuating fever and general malaise. Crohn's disease has a tendency to cause fibrosis, strictures and fistulae within the bowel. These processes may result in major complications, including small bowel obstruction, abscess formation, haemorrhage, entero-cutaneous and enteric fistulae.



In addition about 15% of Crohn's disease patients suffer from extra-intestinal symptoms these include erythema nodosum, peripheral arthritis and ocular lesions. Less commonly (<5%) patients report pyoderma gangrenosum, primary sclerosing cholangitis, renal complications and ankylosing spondylitis.

Some of these manifestations occur during active phases of the disease and respond to treatment of the bowel disorder, others ( e.g. ankylosing spondylitis and hepatic complications) appear completely unrelated to disease activity (Allan, 1993).

#### **1.5.4 Sexual dysfunction**

There is evidence of substantial sexual dysfunction amongst women with Crohn's disease (Moody et al. 1992). Although this is disputed by Moody and Mayberry (1993) who concluded that IBD does not adversely affect personal relationships although patients commonly report anxieties about faecal incontinence, abdominal pain and diarrhoea during sexual intercourse. These findings are consistent with other previously published studies (Gazzard et al. 1978).

**1.5.5 Assessment of Crohn’s disease activity**

Objective scoring of disease activity is important in the assessment of disease severity and response to treatment. The most commonly used activity assessment tool is the Crohn’s Disease Activity Index (CDAI) which was developed for the National Co-operative Crohn’s Disease Study. The CDAI incorporates factors known to be important indicators of disease, and correlates well with physicians’ appraisal of disease activity (Best et al. 1976; Best et al. 1979; Summers et al. 1979). The CDAI scoring regimen is presented in Tables 1.2 & 1.3. Symptoms, physical and laboratory manifestations of Crohn’s disease are recorded and assigned a weight.

Table 1.2

Classification of disease severity using the CDAI in Crohn’s disease

	Mild disease	Moderate disease	Severe disease
Score recorded	<150	150-250	>250

The Harvey Bradshaw score and Dutch activity index are also widely used in clinical studies (Harvey and Bradshaw, 1980; Van Hees et al. 1980).

Table 1.3 Crohn's Disease Activity Index scorecard

(x2)	1	Number of liquid or very soft stools in one week.
(x5)	2	Sum of 7 daily pain ratings: 0 = none, 1 = mild, 2 = moderate, 3 severe.
(x7)	3	Sum of daily ratings of general well-being: 0 = generally well, 1 = slightly below par, 2 = poor, 3 = very poor.
(x20)	4	Symptoms or findings presumed related to Crohn's disease: <ul style="list-style-type: none"> <li>a) Arthritis/arthritis</li> <li>b) Skin/ mouth lesions, pyoderma gangrenosa/erythema nodosum</li> <li>c) Iritis/uveitis</li> <li>d) Anal fissure, fistula, or perirectal abscess</li> <li>e) Other bowel-related fistula (e.g.,enterovesicle)</li> <li>f) Fever over 37.8C.</li> </ul>
(x30)	5	Use of loperamide or other opiate for diarrhoea: 0 = no, 1 = yes.
(x10)	6	Abdominal mass: 0 =absence; 0.4 = questionable; 1 = present.
(x6)	7	47 minus haematocrit (males); 42 minus haematocrit (females)
(x1)	8	100 x [minus (body weight/standard weight)]

## **1.6 Treatment of IBD**

The treatment of Crohn's disease and ulcerative colitis encompasses a multi-disciplinary approach including drug therapy, dietary manipulation, replacement of nutritional deficits and surgery. A holistic approach involving psychosocial aspects is important in improving quality of life and this is addressed in detail in this study.

### **1.6.1 Drug therapy**

The major medical therapy for active disease is to treat with corticosteroids, such as prednisolone, and when the acute disease has settled to maintain remission with compounds containing 5-aminosalicylic acid. Azathioprine is used as a 'steroid sparing agent'. Anti-diarrhoea agents, anti-spasmodics, and analgesics are also sometimes used to reduce symptoms without affecting disease activity.

#### *Corticosteroids*

The main role of corticosteroids in the medical management of IBD is to suppress acute inflammation of the gut. Currently hydrocortisone, prednisolone or methylprednisolone are used for severely ill patients in high dose equivalent to 60-80 mg of prednisolone a day. Oral prednisolone in doses of 40-60 mg a day are effective at achieving remission in less severely ill patients.

The new steroid preparation, budesonide is as effective as prednisolone in treating active disease, but because it is then efficiently removed from the

circulation by hepatic metabolism it has few steroid-related complications (Greenberg et al. 1994). Topical corticosteroids available as foams, suppositories and enemas are a useful treatment for inflammation of the distal colon, anal canal and perianal skin.

#### *5-Aminosalicylic acid compounds*

Maintenance of remission is therefore an important aspect of the long term management. Sulphasalazine is a dimer comprising the sulphonamide, sulphapyridine, and 5-aminosalicylic acid (5-ASA). Sulphasalazine is one of the mainstays of maintenance therapy in IBD, it reduces the frequency of recurrent attacks, and is effective over many years.

The reported dose related side effects of sulphasalazine include nausea, vomiting, diarrhoea, azospermia and headaches and occur in up to 20% of patients. In cases of sulphasalazine intolerance, hypersensitivity or male infertility the use of mesalazine or olsalazine is indicated. These drugs are appreciably more expensive than sulphasalazine, but are much better tolerated. Clinical trials indicate that the 5-ASA preparations, mesalazine, olsalazine and sulphasalazine are equally efficacious in maintaining remission of ulcerative colitis (Ireland et al. 1988; Mulder et al. 1988). In Crohn's disease the drug is only of value in colonic disease, since the active moiety is released by the colonic bacteria. The newer aminosalicylates, particularly "pentasa", which are released in the ileum as well as the colon, may have some value in preventing relapse of small bowel disease.

### *Combination therapy*

With two groups of drugs highlighted as being effective in the treatment of active Crohn's disease, it is reasonable to ask whether or not the beneficial effects of glucocorticoids and 5-ASA compounds are additive. Remission can be induced more readily by sulphasalazine combined with prednisolone than by sulphasalazine alone (Rijk et al. 1991).

### *Immunosuppressants; Azathioprine and 6-Mercaptopurine*

6-Mercaptopurine (6-MP) is a purine antagonist which interferes with nucleic acid synthesis. Azathioprine is largely converted to 6-MP in the body and both drugs have similar clinical effects. Both drugs act slowly over several months and exert a steroid-sparing and anti-inflammatory effect in patients with chronic active Crohn's disease. Azathioprine is used extensively in Crohn's disease patients who have reported side effects whilst using steroids, or for those who relapse rapidly when steroids are reduced. Azathioprine also appears to be useful in maintaining remission in Crohn's disease (Ewe et al. 1993; O'Brien et al. 1991). Reluctance to use these drugs is primarily related to their potential toxicity and in one large controlled study about one in ten patients reported that they were unable to take these drugs because of side-effects (Singleton et al. 1979). Azathioprine has also been shown to be of use in the treatment of ulcerative colitis (Steinhart et al. 1990; Adler and Korelitz, 1990).

## *Antibiotics*

Antibiotics are attractive as a potential treatment for inflammatory bowel disease as they may reduce secondary infection and reduce the antigenic stimulus of enteric bacteria. Metronidazole has a marked anti-bacterial action against anaerobic organisms, such as *Clostridium difficile*. Treatment of Crohn's disease with metronidazole as a primary therapy has shown it to be superior to placebo and as effective as sulphasalazine (Sutherland et al. 1991; Ursing et al. 1982).

Ciprofloxacin is a second antibiotic that anecdotally appears to be useful in the treatment of Crohn's disease. Fistulae and perianal symptoms may resolve and it is suggested that ciprofloxacin may function via an immunological mechanism as well as its role as an antibiotic. In a three month trial, a ciprofloxacin and metronidazole combination induced remission in patients with active Crohn's disease (Peppercorn, 1995; Turunen et al. 1993).

### **1.6.2 Nutrition**

Malnutrition is a major problem that frequently complicates IBD patients of all ages. This is a multi-factorial process resulting from anorexia, malabsorption and secretory losses from the bowel. Thompson highlighted three approaches to nutritional care in ulcerative colitis and Crohn's disease; general measures, exceptional measures and nutrition as a treatment (Thompson, 1993).

General measures imply a balanced diet containing sufficient calories, vitamins and minerals to sustain healing and correct or prevent deficiencies. Exceptional measures are those necessary to maintain nutrition in an acutely ill patient, normally administered via enteral or parenteral routes.

Total parenteral nutrition (TPN) has been demonstrated to be effective in controlling the disease activity and complications of Crohn's disease (Muller et al. 1983). Elemental diets have also been shown to alleviate disease activity in addition to improving nutritional status (Bernstein and Shanahan, 1996). Wright and Scott (1997) reported elemental diet to be as effective as oral corticosteroids in the treatment of active Crohn's disease. O'Brien et al (1991) suggested a role for elemental diet as a adjunct to corticosteroid, although confirmatory studies are still required. Seidman et al (1986) viewed elemental diet therapy as safe, well tolerated and effective in the treatment of acute Crohn's disease, its only major disadvantage is its unpalatability, a problem which can be overcome by nasogastric infusion.

The lower cost and the reduced risk of complications with elemental diet favour its use over TPN in patients with Crohn's disease. The only circumstances in which TPN therapy is favoured are limited to patients with a very short gut or when there is near complete obstruction. Elemental diet has not been shown to be effective in the treatment of patients with ulcerative colitis (Cezard and Messing, 1993).



The mechanisms by which such nutritional therapies improve disease activity are unclear but may involve the intestinal adaptive response to 'bowel rest', immunologic effects, and nutritional factors. Although nutritional therapies are effective as a method of inducing remission in Crohn's disease relatively little is known about their use for the maintenance of long term remission.

### **1.6.3 Surgical management**

The majority of patients with ulcerative colitis can be successfully managed by careful medical management, although a minority still require surgical treatment either for fulminating disease, because they are unresponsive or have side effects from medical treatment, or because quality of life is poor. In contrast several studies have shown that the majority of Crohn's disease patients will require between two and four operations (Keighley and Ambrose, 1982; Higgins and Allan, 1980). Surgery is indicated in both Crohn's disease and ulcerative colitis in severe acute disease which fails to respond to medical management for the complications of the disease, and for poorly controlled disease despite all forms of medical treatment, leading to chronic ill health and malnutrition.

Surgery can involve major intestinal resection with a resulting intestinal stoma. Patients may be concerned about the influence of this on their social, sexual and family lives (Whelton and Findlay, 1971). For patients with ulcerative colitis undergoing colectomy, the formation of an ileo-anal pouch may overcome the need for a permanent ileostomy. These psychosocial issues are given further consideration in this study. Surgical treatment is an important and established

method of treatment and there is no evidence that the role of surgery is diminishing, despite the advances of drug therapy (Alexander-Williams, 1983).

Not all surgical operations for Crohn's disease involve major intestinal resection. Surgical management may be required simply to drain an abscess, assess painful disease under anaesthesia, excise a fistulous track, refashion a stoma or construct a stoma without resecting the bowel. Obstructed bowel may be preserved by stricturoplasty.

**CHAPTER TWO**  
**QUALITY OF LIFE**

## **2.1 Introduction to quality of life**

The world can function without it (quality), but life would be so dull as to be hardly worth living. In fact, it would not be worth living .

(Pilsrig, 1974)

Quality of life (QOL) is a vague term, the origin of which is unknown and the meaning of which is difficult to define. It portrays the essence of attitudes and behaviours in the physical, social and emotional domains of lifestyle. Shin and Johnson (1978) defined QOL as “the possession of the resources necessary to the satisfaction of individual needs, wants and desires, participation in activities enabling personal development and self actualisation and satisfactory comparison between oneself and others”. Patterson (1975) adopted an alternative approach based upon measurement of general health, performance status, general comfort, emotional status and economic status. Therefore, as QOL means so many different things to so many people its usefulness as a meaningful descriptor is seriously compromised.

Furthermore, only part of QOL is a consequence of physical health status. McGee et al.(1991) questioned patients at a follow-up gastrointestinal out-patient clinic to ascertain the relative importance of a range of aspirations and concluded that family, work, social and leisure and health were the most frequently nominated domains of lifestyle. Good physical health was not perceived as the most important aspiration. However in individuals with chronic

illness, ill health is a significant contributor to QOL and the field of health-related quality of life (HRQOL) has subsequently emerged (Berg, 1975).

QOL was introduced by Medline as a heading in 1975, and was accepted as a concept by Index Medicus in 1977. This was followed by acknowledgement and acceptance by several scientific bodies. Bech (1992) describes an explosion of interest in HRQOL measurement within the medical profession since the early 1970's. Much of the early HRQOL research was conducted in relation to oncology care but in recent years much interest has developed in relation to other diseases (De Haes and Kippenberg, 1985). Significant advances in medical and surgical practice have led to prolonged life but in many patients this may be at the expense of mutilating surgery or the unpleasant side effects of drug therapy. Consequently health professionals have become aware that QOL is at least as important as the duration of survival in the provision of health care (Torrance, 1986b).

## **2.2 Health related quality of life : an overview**

### **2.2.1 Introduction**

The theoretical framework of HRQOL is largely based on a multi-dimensional perspective of health based upon a combination of physical, psychological and social well-being. The physical dimension is concerned with the effects of illness on a person's ability to carry out normal activities of daily living. The psychosocial dimensions deal with the effects of illness upon emotion and the social interaction with friends, family, work colleagues and the community.

Spitzer (1987) emphasised that some psychosocial elements are more important than physical symptoms in patients suffering from chronic illness. Ware (1987) further argued that there are five inherent dimensions in HRQOL. These are physical health, mental health, social functioning, role functioning and general well-being .

The most comprehensive definition of HRQOL is provided by the World Health Organisation Quality of Life Group (WHOQOL,1991), which provided a definition including individual perceptions and relationships with the environment :

‘Quality of life is defined as an individual’s perception of their perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationships to salient features of the environment’.

A briefer, but equally acceptable definition of HRQOL is provided by Shipper et al. (1990) as ‘the functional impact of an illness, and its consequent therapy. upon the patient, as perceived by the patient’. This distinguishes HRQOL from other forms of QOL assessment, as patient-reported subjective assessments evaluating sensory function, (including pain and discomfort), mobility, activities of daily living, physical, social, emotional and cognitive function. Health and disease related attitudes and satisfaction are also important components of HRQOL.

Fitzgerald et al. (1992) discussed the plausible applications of HRQOL measurement within chronic illness as including assessment of individual or patient population needs, health care delivery, natural history of the disease, therapeutic efficacy in clinical trials and as an essential constituent of cost-utility analyses.

### **2.2.2 Measurement**

A review of the methodology of HRQOL assessment was undertaken by Aaronson (1989). Several key areas which require specific attention when addressing the issue of HRQOL were identified including;

- i) who should measure HRQOL ?
- ii) psychometric properties of HRQOL measurement tools.
- iii) type of measurement
- iv) a review of generic and/or disease-specific instruments.

#### **i) Who should measure HRQOL ?**

Whether HRQOL should be assessed by the patient or by a health professional remains controversial. Many clinicians believe that their own observations are more useful than the patient's views as they provide an objective perspective. However, the subjective view of the patient's own well-being is important and should be viewed as a reliable index of health status. Bowling (1991) reported consensus among health researchers who believe that health outcome should

incorporate the patients' perspective, not simply in terms of whether or not a treatment or therapy is successful, but more globally in relation to the patients perceived mental and physical well-being. Slevin et al. (1988, 1990) underlined the need to include the patient's perspective by demonstrating that there are wide discrepancies between doctors' and patients' ratings of outcome in relation to many medical therapies. They argued against observer ratings of another person's quality of life, because an individual's values and opinions cannot be assumed. In a study of anti-hypertensive drug therapy all clinicians perceived that their patient's quality of life was improved upon the commencement of anti-hypertensive therapy. In contrast 75 % of patients' relatives thought that it was worse, 8% of the patients felt worse and 44% felt no improvement, demonstrating a poor correlation between professionals' and the patients' own assessments (Jachuk et al. 1982). However, Pincus et al. (1989) compared patients' subjective assessment of QOL with physicians' global assessment of disease activity in 259 out-patients with rheumatoid arthritis and concluded that patients' assessment of QOL in this chronic illness correlated well with the physicians' clinical observational.

### **2.2.3 Psychometric properties of HRQOL measurement tools**

All QOL assessment tools or health status indices require rigorous evaluation prior to their acceptance as valid diagnostic or evaluative yardsticks in disease assessment. Psychometric assessment is the evaluation of the quality of an



instrument, based primarily on the evidence of its validity and reliability (Polit and Hungler, 1995c).

### *Validity*

Validity of an index or questionnaire is a quantitative assessment of how well it measures the phenomenon of interest. There are several accepted definitions of validity, which substantially overlap:

#### *Criterion validity*

Criterion validity, or predictive validity, is the comparison of a new index or questionnaire against an accepted reference measure that evaluates the same or similar features. For example, the performance of the Harvey-Bradshaw index was compared with the Crohn's Disease Activity Index (CDAI). This was only valid because the CDAI is an accepted index of activity. If the CDAI were not a reliable measure of disease activity an alternative approach would have been necessary.

#### *Construct validity*

Construct validity is an assessment which relates scores or changes in scores of a new index to a hypothesis, concept, or prediction of what the index is measuring.

#### *Content validity*

Content validity assesses the degree to which an index measures the full spectrum of problems caused by a particular disease. In IBD, this assessment might include physical, emotional and social problems.

### *Reliability*

Reliability is concerned with the consistency of a test, index, or questionnaire when readministered under similar conditions on separate occasions. The reliability of a measuring instrument that yields quantitative data is a major criterion for the assessment of its quality. Essentially, the reliability of an instrument is the degree of consistency with which the instrument measures the attribute under question. The notion of reliability is often taken to entail two separate aspects, external and internal reliability. External reliability refers to the degree of consistency of a measure over time. Test-retest reliability, that is administering a test on two separate occasions to the same group of subjects, provides assessment of external reliability. Internal reliability raises the question of whether a scale is measuring a single idea and is conveniently measured by Cronbach's alpha calculating the average of all possible split-half reliability coefficients of a scale (Bryman and Cramer, 1994).

### *Responsiveness*

Responsiveness is the facility of an index to reflect important changes over time or after an intervention. Although a measure may be responsive to changes it may not accurately reflect these changes.

### *Sensitivity*

Sensitivity refers to the ability of a measurement to reflect degrees of differences.

The components of validity, reliability, responsiveness and sensitivity testing are critical in the evaluation of HRQOL questionnaires and assessment tools.

#### **2.2.4 Types of HRQOL measurement**

The questionnaires used to measure HRQOL ranges from single-item questions to batteries of single-item questions and complete measurement scales. Global questions, such as, 'How do you rate your quality of life today ?' are of limited value. They categorise patients but do not explain why a patient is placed in a particular category. Global measures are nevertheless important in that they do provide constructs against which subjective measures may be validated.

The single-item approach is popular because it is easy to administer and analyse, but it is doubtful whether single questions can effectively measure specific domains and reliability is also difficult to assess. This was emphasised by Ware et al. (1993) in their assessment of the Short Form Questionnaire (SF36) in which single-item measures fell short of the minimum level of precision needed for testing a hypothesis. The superiority of multi-item scales over single-item assessment was demonstrated by Manning et al. (1982) who used standardised, well tested scales, with sound psychometric properties in an assessment of IBS symptoms.

Garrett et al (1990a) illustrated that controversy surrounds the debate as to whether generic and/or disease specific measures should be used in the assessment of HRQOL in IBD. Drummond (1987) stressed the importance of generic instruments in assessment of chronic illness, but also highlighted that they are not equally applicable to all chronic conditions. McKenna (1993)

predicted that the role of generic measures will diminish as more disease-specific measures are developed; he viewed disease-specific measures as superior because they avoid irrelevant questions and have greater sensitivity. Guyatt et al. (1989) underlined the value of disease specific questionnaires as a supplement to generic tools in the detection of clinical changes.

### **2.2.5 Generic Health Status Instruments**

Generic instruments are measures which implicitly or explicitly aim to gauge broad measures of health status. They include, the Sickness Impact Profile, the Nottingham Health Profile and the Short-Form 36 (Bergner et al. 1981; Hunt, 1988; Brazier et al. 1992). These questionnaires have been developed to cover specific components of HRQOL in a systematic and unified manner. They are of most value for assessing multiple medical or severe diseases, the elderly, disabled, or handicapped. They are also of use in the evaluation of conditions which lack objective end points such as the irritable bowel syndrome. Generic scales encompass physical, medical, and social aspects of health. Garrett et al. (1990) suggested that generic measures have clinical value because they may reveal symptoms or restrictions of activities that physicians do not elicit from patients. They also permit a more sensitive quantitative assessment of the efficacy of treatment than disease activity indices (e.g. CDAI).

The following section provides a brief overview of currently available generic measures of health status;

*The Sickness Impact Profile (SIP) / Functional Limitations Profile (FLP) :*

The SIP, adapted for the UK as the FLP, was developed as a measure of perceived health status across a wide range of health problems and diseases and across a wide range of demographic and cultural groups (Charlton et al. 1983). SIP measures 'sickness-related dysfunction' rather than disease and is based upon the impact of sickness on daily activities and behaviour, rather than upon feelings and physical symptoms. It incorporates questions of physical, emotional and social well-being. One hundred and thirty six items refer to illness-related dysfunction in 12 areas; work, recreation, emotion, affect, home-life, sleep, rest, eating, ambulation, mobility, communication and social interaction. Read et al. (1987) showed that the SIP was both valid and reliable. Fitzgerald et al. (1992) stated that the SIP was very lengthy and unwieldy in the assessment of rheumatology patients. In addition the SIP is only applicable to people who are regarded or who regard themselves as ill.

In a study by Drossman et al. (1989) the SIP was completed during a clinic visit by 87 patients with Crohn's disease and 63 with ulcerative colitis. Patients with IBD experienced more moderate functional impairment in the social and psychological than in the physical dimensions. Crohn's disease patients reported psychosocial dysfunction to a greater degree than ulcerative colitis. Farmer et al (1992) recorded similar findings, including higher morbidity in Crohn's disease than in ulcerative colitics. The sub-group of Crohn's disease patients who had undergone surgery recorded the worst scores. Irvine (1995) warned that these studies, which use the SIP at a single visit, should be interpreted with caution, as they are subject to considerable bias and measurement error.

Despite good psychometric properties, O'Brien et al. (1988) rejected the SIP for their UK based heart disease study on the basis of its length, and chose instead to use the more concise Nottingham Health Profile (NHP).

*Nottingham Health Profile.*

The NHP was developed in the UK in the early 1980's and is based on popular perceptions of health status (Hunt, 1988). The conceptual basis of the NHP was to reflect lay rather than professional definitions of health. It is not an index of disease, illness or disability but a measurement of how individuals feel when they are experiencing various degrees of ill health. It is not a comprehensive measure of HRQOL. However, as a survey tool it is useful in determining whether a health problem is present. This is achieved through multiple assessments; a functional-disability scale, symptom and pain indices, a measure of psychological disturbance, quantitative and more qualitative methods upon social functioning. The NHP is designed for simple self-completion. It is concise and easily administered. It has been used to evaluate the outcome of many therapies including the perceived health status of patients before and after undergoing surgery. The NHP has satisfactory content and criterion validity in physical, social and emotional spheres. In addition, two studies examining osteoarthritis and peripheral vascular disease, using test-retest techniques, administering the NHP on two occasions to the same patient group and demonstrated it to have acceptable levels of reliability (Jachuk et al. 1982). However, Kind and Carr-Hill (1987) suggested that the NHP may be relatively insensitive since it cannot detect low levels of morbidity.

### *Short-Form 36 (SF36)*

SF-36 is a short, generic measure of subjective health status which is psychometrically sound and applicable to a variety of health care settings. It is a self-completed questionnaire which comprises 36 items measuring eight distinct dimensions including; physical function (10 items), social function (2 items), mental health (5 items), role limitation due to physical problems (4 items), energy/vitality (4 items) role limitation due to emotional problems (3 items), pain (2 items), and health perception (5 items). Item scores for each of these dimensions are rated from 0 per cent ( poor health) to 100 per cent (good health).

The UK version of the SF-36 has been slightly modified from the original US version. The changes comprise of language differences and allow for a slight alteration of positioning and scoring of one of the social functioning items in order to facilitate reliability and ease of administration (Brazier et al. 1992).

Garrett et al.(1993) assessed the validity, reliability and acceptability of the SF-36 in a broad sample of patients in the north-east of Scotland. Over 1700 patients, with one of four conditions (low back pain, menorrhagia, suspected peptic ulcer, or varicose veins) were compared to a control group of 900 members of the general population. The SF-36 satisfied rigorous psychometric criteria for validity and internal consistency. Despite this, they recommended that the SF-36 should not be used as a self-contained questionnaire in health assessment but suggested that it should be used in conjunction with disease

specific tools. These authors highlighted the need for further scrutiny of combination generic and disease-specific measurements.

Ware et al. (1993) reviewed the testing and psychometric properties of the SF-36 and found that it had good construct validity and was more sensitive to changes in poor health than the NHP. The SF-36 was able to discriminate between groups with differing degrees of physical disability.

A factor analysis of SF-36 provided strong evidence for the conceptualisation of health underlying the SF-36. Some scales measure physical health, some measure mental health and others measure both. Factor analysis is a multivariate statistical technique that analyses the internal structure of a set of variables to identify any underlying constructs, the purpose of which is to summarise and reduce data to determine inter-relationships among a large number of variables (Hair et al. 1987). Not all research involving the SF-36 has been favourable towards its use. For example McHorney et al. (1992) reported deficiencies in the bodily pain score in a cohort of patients with knee conditions. Anderson et al. (1993) criticised the physical functioning scale because it concentrates upon mobility at the expense of performance of daily activities.

#### *Time Trade Off Technique*

The time trade off technique (TTOT) provides a 'utility measure' of HRQOL. TTOT evaluates the patient's perception of existing health in comparison to death. The TTOT asks patients to choose between living out the remainder of their life in their current health status or living a shorter period of time in perfect health. This permits the calculation of a 'utility' which estimates the subject's



perceived current health status between two extremes; 0.0 (death) and 1.0 (perfect health) (Torrance et al. 1972; Torrance, 1986a). For example a 25 year old with active Crohn's disease is given the choice of 50 years of continuing ill health but who opts for 40 years of perfect health would be assigned a utility of  $40/50$  or 0.8.

Among the possible criticisms of Torrance's cost-utility analysis in health care are the assumptions that health states are chronic and that death is the worst possible outcome. Fallowfield (1990a) stressed the lack of classification within the TTOT for the important psychosocial variables affecting quality of life since scenarios tend to emphasis the physical dimension. She concluded that the TTOT provides a 'hypothetical game' which assesses perception and not function and it fails to identify the underlying reasons for HRQOL impairment. In a prospective surgical study 93 patients were assessed one year after colectomy with either conventional ileostomy, Koch pouch or pelvic pouch. It was concluded that despite the fact the utilities recorded ranged from 0.86 to 0.97 there was no statistical significance between the three procedures (McLeod et al. 1991).

Although the TTOT is a useful utility tool for detecting large scale changes over time or large between-group differences, like other generic instruments it may not detect small differences which may exist between similar groups. The TTOT also assumes that people are rational and realistic when making an assessment of their quality of life. There has also been very limited psychometric testing of the TTOT.

## **Summary**

Generic scales implicitly or explicitly aim to measure HRQOL. They have evolved in order to make comparisons between varying conditions, to broaden outcome indicators and because of the slow development of disease specific questionnaires.

Hutchison and Fowler (1992) pointed out that the main constraint of all generic scales was their inability to identify condition specific aspects of disease. Of the generic measures covered in relation to IBD the unsatisfactory length of the SIP, the relative insensitivity of the NHP to detect low levels of morbidity and the hypothetical nature of the TTOT confirm the SF36 as the most appropriate generic test for measurement of HRQOL. The SF36 is internally consistent, provides a valid measure of the health status across a wide range of patients.

### **2.2.6 Disease specific measures in IBD**

HRQOL assessment in IBD has been performed using a variety of methods with varying degrees of rigor. Objective markers of disease activity such as the CDAI and the Harvey-Bradshaw Index are largely based upon assessment of physical components of disease and do not include psychological measurements (Garrett and Drossman, 1990a).

Talal and Drossman (1995) argued that psychological status influences a patient's response to chronic illness. Indeed there is no clear relationship between laboratory data, such as haematocrit, ESR and overall functional ability.

Drossman stated that psychological and social disability may be at least as important as the physical symptoms. Dependence upon physical factors alone may underestimate the full impact of IBD on the patient (Drossman, 1994). Kunsebeck et al. (1990) concluded that socio-economic status and disease activity indices are relatively easy to measure but, like Drossman, commented that they are only part of overall HRQOL because they do not consider personal perception.

Many methodological flaws existed in the preliminary studies which measured HRQOL in IBD and the conclusions of these studies are therefore limited (Mitchell et al. 1988). These studies were primarily observational, uncontrolled and most did not use standardised or validated methods to assess the psychological dimensions of HRQOL. These studies emphasised the need to quantify the psychosocial aspects of IBD. HRQOL mainly relies upon the patient's own perception of health status. This differs from other validated measures of disease activity because it examines subjective experience of health as the 'gold standard', and includes psychosocial factors. Personal determinants of HRQOL include the patient's own assessment of well-being, daily functioning, psychological state, job satisfaction and interpersonal relationships. Measurements of such determinants requires the use of validated questionnaires. Several types of instruments have been developed to measure HRQOL in IBD. The simplest are categorical grades of function which define the proportion of subjects experiencing good, fair or poor HRQOL. Farmer et al. (1985) were amongst the first to measure HRQOL in a large series of patients with Crohn's

disease (n=592). Forty per cent of patients experienced good, 50% fair and 10% poor QOL. Patients with Crohn's disease were more likely to have experienced good HRQOL if they had not undergone surgery. The preliminary study described a previously unappreciated degree of dysfunction, it only provided a snapshot view of QOL, and follow-up data was not reported.

Mallett et al. (1978) earlier reported a sophisticated account of dysfunctional problems in patients with ulcerative colitis. Much of the early HRQOL research in relation to IBD concentrated upon the consequences of surgery. For example Meyers et al. (1980) identified dysfunctional problems following surgery, particularly affecting the sub-group of patients with stomas. Irvine et al. (1995) commented that earlier studies of HRQOL in IBD, were cross-sectional assessments which could not provide an adequate summary of a very complex disease.

To provide a more representative sample of HRQOL in IBD, Drossman et al. (1991b) evaluated the health status of a national sample of patients with IBD who were members of the Crohn's and Colitis Foundation of America (CCFA). These patients provided a self-selected group with a wide range of disease severity and who were typically concerned enough about their disease to join a national organisation. In 997 patients, moderate psychological and social dysfunction affected recreation, sleep, rest and daily work. Overall Crohn's disease patients reported poorer health status and had more work disability than those suffering from ulcerative colitis.

The Cleveland Clinic questionnaire, developed and implemented by Farmer et al. (1992), primarily assessed activities of daily living rather than specific medical symptoms. Using a direct-interview technique, 164 IBD patients (94 ulcerative colitics; 70 Crohn's disease) were evaluated for QOL. The Cleveland Clinic questionnaire consists of 47 items in four categories; functional/economic, social/recreational, affect / life in general and medical/symptoms. Construct validity of the questionnaire correlated well with scores derived from the SIP, a generic measurement of overall health status. QOL in Crohn's disease was worse than that in ulcerative colitis. Patients who had undergone surgery perceived their QOL to be more impaired than those who had no surgical intervention.

Results of studies using generic HRQOL instruments at a single visit must be interpreted with caution since they may be subject to considerable bias and measurement errors, mainly related to the characteristics of the population sampled.

The Rating Form of IBD Patient Concerns (RFIPC) is a specialised questionnaire that identifies and prioritises the 25 most important worries and concerns of IBD patients (Drossman et al. 1991a). The RFIPC contains four clinically relevant category scores, namely; disease-related, body-related, inter/intrapersonal and sex-related, which are measured on visual analogue scales.

Drossman et al. (1989) applied the RFIPC to a sample of 150 IBD patients (63 ulcerative colitis/ 87 Crohn's disease) and reported that the major problem areas

for individuals with IBD were related to surgery, energy/fatigue, and the body image and psychosexual consequences of having a stoma. Drossman et al (1989) concluded that ulcerative colitis and Crohn's disease patients had similar concerns, except that ulcerative colitis patients were more concerned with loss of bowel control and developing cancer, whilst Crohn's disease patients were more concerned with pain and fertility. The consistency of these findings provided a degree of validity, and attested to the potential use of the RFIPC as a measure of patients worries and concerns. Garrett (1990a) and Drossman et al (1992) found the RFIPC to be a potentially valuable measure of health status, which correlated well with other measures of health status. These included the clinicians global assessment, functional impairment and number of hospitalisations. However the same authors highlighted several methodological flaws within the RFIPC. These flaws included the diverse content areas of the questionnaire and the need for extended validity and reliability data checks to address the specificity of the RFIPC.

The ulcerative colitis/Crohn's disease (UC/CD) Health Status Scale was developed to discriminate mild from severe illness and to measure health care use, daily function, and psychological distress. Love et al. (1992) prospectively evaluated the subjective status of 182 relatively well ulcerative colitics derived from the CCFA register. The assessment was based upon a self-completed questionnaire containing 36 questions relating to five dimensions: systemic symptoms, bowel habit, functional impairment, social impairment, and emotional function and this was combined with a global assessment. The results

suggest that quality of life in these patients was worse than that of 48 age and sex matched controls.

Guyatt et al. (1989) developed an 'Inflammatory Bowel Disease Questionnaire' (IBDQ) as they felt that previous HRQOL instruments had not adequately addressed socio-psychological aspects of outcome. The IBDQ examines four aspects of patient's lives: symptoms directly related to the primary bowel disturbance, systemic effects, emotional and social function. Ninety-seven patients with IBD described problems experienced as a result of their disease, and these were used to construct the disease specific questionnaire.

The IBDQ was designed to address areas of function that are important to patients. The questionnaire was designed to be short and simple to administer (Krishner and Guyatt, 1985). Each question contains 7-point Likert scale response categories (relating to frequency, severity and satisfaction) with 7 = 'best function' and 1 = 'worst function'. A Likert scale is a rating system which is subdivided numerically into a series of ordered responses. Scores are summed to produce a total for each of the four aspects of lifestyle. In preliminary studies by Guyatt et al. (1989) 61 IBD patients were evaluated on two occasions one month apart. Preliminary assessment of the IBDQ demonstrated high validity, reliability and responsiveness in its application, particularly in relating changes in IBDQ to changes in the activity of Crohn's disease.

However, the patient sample used to develop this instrument was selected for convenience, possibly reflecting a selection bias. It was based on an assessment of patients in remission, and ileostomy and proctitis patients were excluded

from the analysis. These patients form an important sub-group as they may suffer from significant impairment in psychosocial activity due to symptoms of urgency and body image anxiety. The absence of a control group was a further methodological flaw in the development of Guyatt's original IBDQ.

The validity, reliability and responsiveness of the IBDQ was examined in a randomised controlled trial reported by Irvine et al (1994). Three hundred and five Crohn's disease patients, from 11 tertiary hospitals participated in a randomised, double-blind trial of low dose cyclosporin or placebo as long term therapy over an eighteen month period. IBDQ and dimensional scores (bowel, social, systemic and emotional) were correlated with objective disease activity scores. Concordance of IBDQ scores were tested in 280 stable subjects and linear regression statistical techniques were employed to evaluate change in IBDQ scores over time. They concluded the IBDQ to be a valid and reliable assessment tool that reflects important changes in the health status of patients with IBD. Subsequent Canadian studies have suggested the development of a five item questionnaire short form IBDQ (IBDQ-SF) derived from the entire 32 item questionnaire (Turnbull et al. 1996a). Turnbull et al. suggested that the IBD-SF is a quick and reliable means to measure QOL in IBD, it correlated well with CDAI and provides a useful clinical assessment tool.

### *Summary*

Disease specific HRQOL instruments in IBD have been generated from lists of problems identified by patients. They provide for a useful comparison among similar groups of patients and measure clinically important changes over time.



Disease specific health status measures tend to be more responsive to change than generic measures and their subjectivity allows for identification of the problems that are most bothersome to patients. Of the disease specific tools covered the IBDQ has been the most extensively evaluated. Preliminary assessment indicated that the IBDQ is a valid, reliable and responsive measure of therapeutic outcome in the assessment of features of disease not embodied by standard disease activity indices (Irvine, 1993). However, despite these findings, it is apparent that further assessment is required for these IBDQ disease specific measures to allow for critical outcome measures and for evaluation of new therapeutic interventions in IBD. There is further scope for the development of briefer easily administered self-report scales, such as IBDQ-SF to assess QOL in IBD within the clinical setting.

### *Conclusion*

Generic tools assess the efforts of a wide range of disabilities. Major defects are relative insensitivity and inapplicability to specific diseases. Disease specific tools are difficult to validate, particularly in IBD where the spectrum of disease is extremely wide and an ideal disease specific questionnaire for IBD has not been developed. Irvine highlights the lack of validated disease-specific instruments with regard to assessment of IBD, and underlines the need for development and evaluation of new HRQOL instruments, both disease-specific and generic, in the assessment of IBD. Such a combination would not only permit comparisons between groups of ulcerative colitis and Crohn's disease patients, but would enable comparison to be made between sub-groups of

patients within each clinical entity, whilst retaining sensitivity to treatment effects (Irvine, 1995).

**CHAPTER THREE**

**PSYCHOLOGICAL ASPECTS OF  
INFLAMMATORY BOWEL DISEASE**

### **3.1 Introduction**

It is recognised that psychosocial factors play a major role in the morbidity of Crohn's disease and ulcerative colitis (Drossman, 1993a). HRQOL assessment has become increasingly important and some attention has moved away from objective markers of physical disease activity, such as the Crohn's Disease Activity Index. Increasing attention is now paid to the patient's subjective views of well-being including, emotional and psychosocial assessment are used to provide a holistic measure of disease severity (Garrett and Drossman, 1990b).

### **3.2 Historical perspective of psychological influences**

Crohn, in his book 'Regional Ileitis', made several links between psychological variables and Crohn's disease (Crohn, 1949). Since the first recognition of Crohn's disease in 1932 gastroenterologists, surgeons, psychologists and psychiatrists have striven to find a relationship between psychological variables and physical symptoms. This link has been examined in four ways;

- 1) Personality associations.
- 2) Psychopathology in IBD.
- 3) Relationship with interpersonal factors.
- 4) Stressful life events leading to onset and exacerbation of IBD.

#### **3.2.1 Personality associations**

The earliest psychoanalytically orientated psychosomatic studies conducted in the 1950's described distinct personality traits linked to IBD. George Engel (1955), the principle proponent of this psychosomatic hypothesis during this

period, believed that patients with IBD have a symbiotic relationship with their mother, mother-substitute, or an individual on whom they are emotionally dependent. Psychoanalysts did not differentiate between ulcerative colitis and Crohn's disease. Engel found IBD patients to be restricted in their interpersonal relationships and this theory was shared by Alexander, a major psychoanalytic theorist of psychosomatic disorders. Alexander et al. (1968) suggested that patients who were biologically predisposed to ulcerative colitis tended to display high levels of dependency and were emotionally immature. Such patients were further described as 'achievement orientated individuals' who were inclined to lose hope easily when frustrated. He suggested that the patient suffering from ulcerative colitis was involved in a hopeless struggle for achievement, with a tendency towards obsessive-compulsive personality traits and that when such an individual is placed in a challenging situation the disease would become clinically manifest. Interest in such psychosomatic models ebbed in the 1960's and they are now discredited because the studies upon which they were developed were found to be methodologically flawed and were subject to investigator bias.

Certain personality traits have been shown to be present in patients with Crohn's disease (Gerbert, 1980). For example, Grace (1953) viewed Crohn's disease sufferers as constantly wishing to 'be rid of' events in their lives. Bockus (1945) concluded that IBD patients were emotionally immature. Ford et al. (1969) described an 'obsessive compulsive' nature and a state of dependency in Crohn's disease. Sheffield and Carney (1976) and Paulley (1977b;1977a)

postulated that personality traits such as repressed rage, suppression of feelings and anxiety are closely associated with Crohn's disease. These studies were viewed with caution by Gerbert (1980) since many of these personality traits are common in any chronic physical illness and are probably not specific to IBD.

Drossman (1994) made several criticisms of such intensive psychoanalytic studies which were based upon only a small number of patients. These criticisms can be summarised as follows:

- 1) Sampling bias: Patients studied in the published trials tended to be self-selected or were selected by referral sources because they exhibited specific traits. They were not representative of the majority of patients with the disease.
- 2) Overgeneralisation: When relatively few instances of a disorder are seen and when the investigator is emotionally involved as a therapist, it may be inappropriate to extrapolate findings from a few subjects to the whole population.
- 3) Rosenthal Effect: In prolonged and emotionally intense relationships, between helper and client, the therapist's expectations tend to be communicated to the client thereby influencing the way they describe themselves.

### **3.2.2 Psychopathology in IBD.**

There have been few studies investigating the interaction between physical and psychiatric symptoms in IBD and those that have been undertaken have produced conflicting results.

Several retrospective studies have reported high instances of psychopathology in Crohn's disease (Stewart, 1949; Whybrow et al. 1968; Hislop, 1974).

Unfortunately retrospective studies have considerable problems such as:

- a) Psychopathology cannot be reliably determined retrospectively and it is very difficult to relate psychomorbidity to the severity of physical illness.
- b) Lack of adequate control groups.
- c) The gathering of information by individuals aware of the patient's diagnosis.
- d) The use of psychiatric labels, for example 'psychoneurotic' as opposed to recognised psychiatric classifications.

Feldman et al (1967a; 1967b) investigated psychopathology in a study involving 34 patients with ulcerative colitis, 19 patients with Crohn's disease, a normal control population and a group of patients with other gastrointestinal disorders. They found that the prevalence of psychiatric abnormalities was equally common in both control groups and the IBD patients.

Goldberg (1970) was the first to use a standardised psychiatric interview of demonstrated reliability to assess psychiatric morbidity in IBD. This questionnaire provided a short self-rating scale of psychoneurotic symptoms and traits which had been validated against clinical categories. Goldberg found no difference in the level of psychiatric symptoms in IBD patients compared to patients with other gastrointestinal diseases (idiopathic steatorrhoea and lactose intolerance).

Hezler et al (1984), using validated DSM III criteria produced by the American Psychiatric Association, found that patients with Crohn's disease had a higher

prevalence of psychiatric conditions (36% depression, 6% obsessive-compulsive symptoms) than medical out-patient disease controls (18% depression, none with obsessive-compulsive symptoms). There was no association between the degree of physical morbidity and the presence of psychiatric disorders. The same workers had previously performed a similar study involving ulcerative colitis patients who were compared to a control group of chronically ill out-patients suffering from other diseases. The prevalence of psychiatric illness was similar in the ulcerative colitics and the controls (26% and 30% respectively) with no evidence of an association between psychiatric illness and physical morbidity (American Psychiatric Association. 1980; Helzer et al. 1982).

Andrews et al. (1987) further examined the interaction between physical and psychiatric symptomology in IBD. One hundred and sixty-two consecutive patients were recruited from an IBD clinic (91 had Crohn's disease, 71 had ulcerative colitis). The presence of anxiety and depression was determined using the Hospital Anxiety and Depression score and a detailed psychiatric evaluation was performed with the DSM III (American Psychiatric Association. 1980).

Andrews et al. like Helzer et al. found no association between physical morbidity and psychiatric illness in ulcerative colitis. In contrast to Helzer et al., patients with Crohn's disease had a significantly increased incidence of psychopathy and there was a clear association between the presence of psychiatric illness and degree of physical morbidity. Thus psychiatric illness was present in half of the patients whose disease was in relapse compared to only 8% of those in remission. In this series, the presence of psychiatric



symptoms adversely affected physical recovery. Seventeen per cent recovered when psychiatrically ill compared to 53% when psychiatrically well. The differing conclusions reported by Andrews et al. and Helzer et al. may relate to methodological approaches. In particular, Helzer et al. serially evaluated patients whilst Andrews et al. reported a 'snap-shot' at one time point.

Talal and Drossman (1995) examined the impact of disease severity upon psychological health in 150 IBD patients and noted that Crohn's disease patients had more psychological dysfunction than patients with ulcerative colitis. Both groups of patients reported difficulties with regard to work, sleep and rest, recreation, social interaction and emotional behaviour. Psychosocial disruption was significantly higher in patients with active disease, and the degree of psychosocial disturbance correlated with the severity of the disease (Drossman et al. 1991b).

Whybrow and Ferrell (1973), concluded that one third of studies showed that Crohn's disease causes significant psychiatric morbidity. Affective symptoms, such as anxiety predominated. Most studies indicate that psychiatric and psychosocial morbidity increase with chronicity and severity in Crohn's disease.

### **3.2.3 Relationships with interpersonal factors**

a) Source of anxiety; Drossman et al. (1991a) reported that IBD patients express concerns about surgery, lethargy, perceptions of body-image and hygiene. The authors concluded that these concerns may influence psychological health. They also showed that ulcerative colitis and Crohn's disease patients have different worries. Crohn's disease patients appeared more concerned with the

impact of their disease upon lifestyle, whereas ulcerative colitis patients more commonly reported fears of cancer (Drossman et al. 1992).

In addition, several psychosocial factors are known to modulate the effects of stress on an individual's response to disease. These include self-confidence, self-reliance and an adequate stable social support system.

b) Marital and sexual dysfunction; Monk et al. (1970), compared marital adjustment in patients suffering from Crohn's disease with that in patients suffering irritable bowel syndrome. Crohn's disease sufferers were less likely to be married than irritable bowel patients. Whether a stable social support system can positively affect outcome in IBD is unknown. Although such information is available in other medical specialities. For example, Berkman et al. (1992) found that patients lacking emotional support had a threefold increased mortality from myocardial infarction compared to patients from a stable social background.

Research into sexual adjustment in IBD has been restricted to the consequences of surgery and largely remains a taboo area which Dlin et al. (1969) states is "rarely discussed openly". Burnham et al. (1977) examined the incidence and nature of sexual problems among members of the Ileostomy Association of Great Britain. The study, which was restricted to married ileostomists, reported that the majority of patients had adapted well to their surgery. Nevertheless, 12% of respondents attributed marital tension, unhappiness, or even separation to the presence of a stoma.

Social and cultural factors may affect how patients adapt to a chronic illness, such as IBD. Fabriga (1992) stated that “the symbolisation of an illness and its causation provide important cultural dimensions in chronic illness.” Negative factors which may hamper an individual’s ability to cope with a chronic disease include abnormal illness behaviour. This is defined by Pilowsky (1986) as “the persistence of a maladaptive mode of experiencing, perceiving, evaluating and responding to one’s health status”. Secondary gain provides a form of maladaptive coping strategy which maximises the benefits that can be accrued from illness. Secondary gain is a normal response in children but is abnormal when it persists into adulthood. It reduces the distress from professional, social and familial responsibilities, resulting in tangible benefits, such as sympathy and attention from others.

c) Employment and Education; Mayberry and Mayberry (1992) examined the social consequences of IBD upon educational attainment and employment prospects. Although IBD patients lost time from their studies due to their disease, this did not affect their academic achievements, as measured by exam success. In this study 83 patients, diagnosed before the age of forty, were examined. Sixty-nine percent were in active employment. Twice as many Crohn’s disease patients, compared to healthy controls, had experienced long spells of unemployment, although relatively few had lost their job because of their disease. Over one third of patients actively concealed their illness from their employer. Mayberry et al. (1992) and Probert et al. (1991) reported similar findings in a study which highlighted employers practical discrimination against

IBD patients. Wyke et al. (1988) conducted further employment based research in which patients said that their disease may have contributed to failure of promotion and impaired career development. In this study patients did not perceive significant employment discrimination due to IBD.

### **3.3 Stressful life events leading to onset of IBD**

The term 'stress' has many connotations and definitions based on a variety of perspectives of the human condition. Lazarus and Dlongis (1983) defined stress as "a state of anxiety produced when events and responsibilities exceed one's coping abilities".

The link between stress and disease was examined by Hans Seyle (1976;1946), who described the 'general adaptation syndrome'. Seyle defined stress as the non-specific psychobiological responses of the body to any demand placed upon it to adapt. He observed that whether a situation was perceived positively or negatively, the body's physiological response or arousal was similar; he argued that one cannot discriminate between 'good' and 'bad' stress. The 'general adaptation syndrome' is the process by which the body tries to accommodate stress by adapting to it in a three stage process. The three stages comprise :

Stage One; Alarm reaction. The alarm reaction describes a 'fight or flight' response. In this stage several physiological responses occur. Initially this involves the nervous and the endocrine systems, followed by cardiovascular, pulmonary, and musculoskeletal responses.

Stage Two; Stage of resistance. The body tries to revert back to a state of physiological calmness, or homeostasis. Because the perception of a threat still

exists, however, complete homeostasis is never reached. Instead, the body stays activated or aroused, usually at a lesser intensity than during the alarm but enough to cause a higher metabolic rate in some organs.

Stage Three; Stage of exhaustion. Exhaustion occurs when one (or more) of the organs targeted by specific metabolic processes can no longer meet the demands placed upon it. In its most extreme form this may lead to organ failure and death.

Selye's general adaptation syndrome outlined the physiological consequences of stress and he identified the pituitary-adrenocortical axis as the major central neuroendocrine mediator of the stress response. Through activation of the hypothalamus there is stimulation of the pituitary gland, which is responsible for secreting several hormones. Adrenocorticotrophic hormone (ACTH) is the most significant in this context, as it stimulates the release of corticosteroids (Johnston and Wallace, 1990). This results in a variety of physiological effects; the most important is response to physical and psychological stress. In addition other effects; including stimulation of gluconeogenesis in the liver, inhibition of glucose uptake by peripheral tissues and suppression of the immune system may be related to IBD.

The relationship between stress and disease involves several factors. These include the cognitive perceptions of the threatening stimuli and the consequent activation of the nervous, endocrine, and immune systems. Study of this interdisciplinary network provides a psychoneuroimmunological model of stress defined by Pelletier and Herzing (1988) as; 'the intricate interaction of

consciousness (psycho), brain and central nervous system (neuro), and the body's defence against external infection and internal aberrant cell division (immunology)'.

The psychoneuroimmunological model of stress differs from that of Seyle. This model incorporates several distinct physiological responses to 'positive' and 'negative' stress. Seaward (1994) defined stress as "the inability to cope with a perceived or real threat to one's mental, physical, emotional, and spiritual well-being which results in a series of physiological responses and adaptations."

The relationship between life stress, illness and disease activity is difficult to measure in clinical practice. The effect of stress upon disease is more easily studied in animals but the results of such studies may not be applicable to man. Animals subjected to stress may develop gastrointestinal abnormalities. For instance Porter et al. (1958) showed the production of chronic gastrointestinal lesions, including chronic colitis, in Rhesus monkeys placed in conditioned anxiety provoking situations. Chalifoux and Bronson (1981) found the cotton-topped tamarin, *Saguinus oedipus*, when held in captivity, develops a colitis which is similar to ulcerative colitis in man. Two hundred and ten cotton topped tamarins held in captivity for a period of three and a half years frequently developed colitis complicated by adenocarcinoma, and this did not appear to be related to dietary factors, infection, or other environmental variables. In a critique of Chalifoux's work, Drossman noted that these animals make considerable social adjustment when removed from their natural habitat and that

the imposition of this social disruption may influence the development of disease (Drossman, 1985).

It is clearly impossible for ethical reasons to perform similar experiments in man but there is evidence linking psychosocial stress to human disease. For example, Karasek et al. (1988) highlighted a strong association between occupational stress and an increased prevalence of coronary heart disease. Salen and Shubar (1967) suggested that psychosocial disruption may contribute to disease susceptibility in IBD. For example, the stress of moving from a nomadic life to government housing may have contributed to the first reported occurrence of ulcerative colitis in Bedouin Arabs, a group in which ulcerative colitis is otherwise extremely rare.

Physiological consequences of stress on the gastrointestinal tract;

All clinical gastroenterologists are aware that psychological stress may trigger IBD relapse and psychological stress often causes gastrointestinal symptoms. Diarrhoea and abdominal cramps are experienced by most individuals during times of stress, for example prior to an exam or interview.

Whitehead et al. (1992) proposed that this physiological response is based upon increased gastrointestinal motility in response to the stressor. Mayer and Gebhart (1994) coined the term 'visceral hyperalgesia' for this phenomenon. The physiological basis for this effect is unknown. Alterations in peristalsis and changes in gastrointestinal secretion are described in the response to psychological stress, but these are almost certainly mediators rather than causative factors (Cooke, 1986; Ader, 1980).

There are many factors, including emotion, that affect gastrointestinal secretion and motility. These may exert their effects via the central nervous system and produce long-term sensitisation of pathways involved in the transmission of visceral sensation. Several neurotransmitters (e.g. acetylcholine) and hormones (e.g. cholecystikinin) are common to both the gastrointestinal tract and central nervous system.

Drossman (1993b) suggested that prolonged exposure to psychological stress can lead to transient changes in immunological function. He argued that IBD could result from dysregulation of the relationship between the CNS and the immunological function of the gastrointestinal tract. Although psychosocial factors may not initiate inflammation in IBD he suggested that they may lead to an abnormal immune response, which affects disease activity .

### **3.4 Stress, personality and coping**

Two main approaches to the study of stress in IBD are described. One line of investigation has examined the causal relationship between stress and disease and the other has examined the effects of relieving stress upon disease activity.

#### **3.4.1 Stress and causation**

One way of relating stress to illness has been to link it to life events. Holmes and Rahe (1967) developed the 'Social Readjustment Rating Scale' (SRRS), an inventory which ranks forty three stressful events with numeric values, from most to least stressful, based upon their capacity to disrupt activities and the degree of readjustment which is necessary following the event. These values are



termed 'Life Change Units' (LCU). In further research using this assessment tool Rahe (1968) showed that the development of minor illnesses, such as colds and 'flu, was linked to life events.

Schroeder and Costa (1984) stated that life event scales are notoriously flawed indices of stress. This was predominately because they cannot differentiate the impact of positive from negative life events. Jenkins et al. (1979) pointed out the inaccuracy of event recall as the major shortcoming of life event scales. Roger and Hudson (1995) were critical of the use of life event scales to assess stress; they argued that if the assumption is made that life events were in some way inherently stressful there would be no need for stress management, as the majority of the life events which occur are unpredictable and beyond the individual's control. The life-event scale approach also implies that individuals would respond in much the same way to similar situations, but the range of observed responses to similar situations shows that individual differences may well be implicated in determining a stress reaction. Roger and Hudson noted wide differences in both physiological and cognitive responses to stress, and these processes are likely to be influenced by a variety of moderating variables, including personality and coping .

### 3.4.2 Personality and stress

Personality has been classified by psychologists as either 'stress-prone' or 'stress-resistant' and individuals with these different characteristics may react very differently to similar stressful events. Type-A, co-dependency and helpless-hopeless are three personality sub-types that have been defined as being stress-prone.

The Type-A Behaviour Pattern (TABP) is characterised by striving for achievement, competitiveness and impatience. TABP may predispose to the development of ischaemic heart disease (Wright et al. 1985).

Rosenman and Friedman (1977) developed a structured interview technique to assess characteristics such as competitive achievement orientation, time urgency, and anger / hostility which are regarded as the primary components of TABP. Much uncertainty over the existence of TABP has arisen from disagreement over the components of the construct. Roger et al. (1995) pointed out that TABP was originally devised in the context of an illness model, where diagnosis declares the presence or absence of disease. By contrast, constructs in the biological sciences apply to the physically healthy and tend to be normally distributed. These authors viewed TABP as unquestionably a behavioural or psychological construct, and suggested that there is no reason to suppose that it comprises types at all. Roger further postulated that Type-A is itself a function of other, higher-order psychological constructs, especially self-esteem and that TABP is in part a compensatory reaction to perceptions of self-worth. Self-esteem interacts with achievement motivation to determine Type-A behaviour.

in individuals with low self-esteem but high motivation to achieve. Anxiety concerning fear of failure results in compensatory mechanisms which are expressed as time pressure or hostility.

Another influential factor in modulating the stress response is 'locus of control'. This concept arose from the observation that individuals give different reasons for events; the cause of an event could be external (luck), internal (ability and effort) or a combination of the two. A person with an internal locus of control has an expectation that he or she will be able to control the environment, either through ability or effort. Someone with an external locus of control expectation believes that outcomes are outside personal control and depend on outside influences. Locus of control has been implicated in a wide range of health-related behaviours, with 'internals' more likely to take a variety of preventive measures than 'externals'. Folkman (1984) showed that personal control modulates affective disturbance and job-strain. A sense of personal control over the environment is one of the principal components of the 'hardy' personality. Kabosa et al. (1982) identified the 'hardy personality' type who in the face of disaster, appears immune to stress. Research on 'hardiness' suggested that having more internal control, or an internal locus of control, may serve as a buffer against stress. However, Meadows (1989) argued that an internal locus of control has been shown to be associated with a greater susceptibility to stress amongst subjects who experienced high levels of life events.

Roger and Raine (1984) studied the role of personality in relation to stress in the context of stimulus intensity control. Stimulus intensity control is a model

which includes neuroticism, extroversion and other personal constructs such as sensation-seeking and augmenting reducing which are thought to reflect underlying differences in basal cognitive or emotional arousal and arousability. Broadbent et al. (1984) reported greater susceptibility to infection amongst highly aroused introverts as compared to extroverts .

Eysenck (1985; 1988) used extroversion and neuroticism to develop a model for explaining differential susceptibility to cancer and to heart disease. His model relied in part on a distinction drawn by Sklar and Anisman (1981) between chronic and acute stress, the former is thought to 'inoculate' or protect individuals against illness, whereas the latter may result in immunosuppression and increased susceptibility. This effect applies only to physical stressors, as Sklar and Anisman state "immunosuppression induced by social stress is not altered under chronic conditions".

Roger (1988; 1992) proposed an alternative approach to define the relationship between personality, stress and physical health. This approach was based on emotion control and emotional rumination or rehearsal. Cameron and Meichenbaum (1982) suggested that continued rumination over emotional distress might contribute to delayed recovery in illness, although they noted that no reliable measurement of emotional styles are available. Based upon these conclusions Roger devised the Emotion Control Questionnaire (ECQ). The ECQ or Attitudes and Preferences questionnaire (Appendix 9) comprises four discriminable scales labelled rehearsal, emotional inhibition, aggression control and benign control. The rehearsal scale measures the tendency to ruminate over

emotional distress, while emotional inhibition refers to the inhibition of experienced emotion. The final two scales, aggression control and benign control were shown to be moderately correlated, and form part of the extroversion factors. Benign control, for example, correlates substantially with established measures of impulsiveness. Roger and Neshoever (1987) demonstrated in subsequent validation studies of the ECQ that rehearsal was strongly associated with physiological and psychological indices of adaptation. The ECQ scales were validated by comparisons with accepted scales, such as Eysenck's Personality Inventory. Roger demonstrated that 'rehearsal' correlated with Eysenck's neuroticism and that 'Emotional Inhibition' was significantly inversely correlated with extroversion. Subsequent work investigated the relationship between the ECQ and physiological reactivity and recovery. Roger and Jamieson (1988) investigated heart-rate recovery following exposure to a moderate psychological stressor. Heart-rate recovery of subjects who scored highly on rehearsal was significantly greater than that of individuals with low scores. Extroversion and neuroticism did not apparently relate to scores for rehearsal. Roger et al. (1995) demonstrated that ECQ scores significantly related to scores of social and psychological readjustment in a range of subjects including prison inmates and peri-natal women. These studies, based at the University of York, led to the development of a work skills and stress management programme, the '*Challenge of Change*'. The programme included a battery of personality scales which were purpose-designed and extensively

validated. The scales, include the four ECQ scales, a locus of control study, a measure of tolerance for change and a scale for assessing the TABP.

### **3.4.3 Coping**

Coping is a critical factor in adaptation to stressful life events. Folkman and Lazarus (1991) defined coping as “cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person”. In order for a cognitive process to be considered coping it must involve a purposeful effort. Shannon (1996) differentiated between adaptation and coping. Feldman (1974) viewed adaptation as coming to terms with the reality of chronic illness; this included letting go of false hope and hopelessness, as well as engaging in a process of restructuring the environment. White et al. (1992) devised a model of psychosocial adaptation in which life events and health status were considered stressors and coping strategies and social support were important factors in the adaptation process. Shannon viewed coping as a component or a ‘subset’ of adapting. Folkman and Lazarus (1991) stated that “the best coping is that which changes the person-environment relationship for the better”.

Coping styles may be involved in the response to stress, and may be influenced by personality. Endler et al. (1994) described coping very generally as a response to negative events, although the responses themselves are often defined in terms of stable traits.

Some researchers have speculated that the effect of a stressor may be buffered by an appropriate coping mechanism, and to an extent, this view reflects popular

belief. The supposed benefits of a “good cry”, or for that matter, a “good laugh” are well known but it less well understood what precisely constitutes an appropriate coping mechanism, and more importantly how to measure such a phenomenon.

### *Measurement of coping*

Coping processes are typically classified as rational or emotional, and within this broad classification a variety of different strategies have been identified. One of the most widely used instruments is the “Ways of Coping” (WOC) questionnaire, designed and then revised by Folkman et al. (1986). The WOC is a 51-item questionnaire which assesses the coping response an individual selects in response to specific stressful situations. Individuals are asked how often they use a range of listed coping responses to manage a specific problem and the frequency of each response is recorded. Of the eight factors extracted from the WOC, half of them comprised fewer than five items which provided psychometric shortcomings for this questionnaire. The WOC questionnaire was used by Drossman et al. (1991b) in an examination of HRQOL in 997 IBD out-patients. In an effort to determine whether the pattern of coping was psychologically adaptive, they examined the relationship between the eight coping styles and the psychological functioning component of the Sickness Impact Profile. Drossman et al. reported that the two coping strategies associated with poorer psychological function and emotional distress were not conspicuous in this patient group.

Endler and Parker (1990) devised the Multidimensional Coping Inventory (MCI) which clarified earlier attempts to identify coping dimensions. Three primary theoretical constructs; task, emotional and avoidance coping were described. Roger et al. (1993) identified a degree of overlap amongst these three dimensions and described a fourth category called detached coping. The Coping Styles Questionnaire (CSQ) or Styles and Strategies questionnaire devised by Roger et al. defined four coping styles called detached, rational, emotional and avoidance (Appendix 8). Rational and detached coping were significantly positively correlated, and both were inversely correlated with emotional coping. To a lesser degree, avoidance coping positively correlated with emotional coping, whilst avoidance and rational coping were weakly inversely related. Avoidance and detached coping were apparently unrelated. Subsequent validation studies of health and social adjustment suggested that detached and rational styles have adaptive outcomes, while emotional and avoidance styles have maladaptive outcomes (Tables 3.1 & 3.2). Studies have shown that coping styles interact with emotional control scales and predict both health and psychosocial adjustment (Roger et al. 1994). The ECQ and CSQ have been used together to investigate the interactive effects of coping styles and emotion control on adaptation. This led to the development of a stress management programme called, '*Challenge of Change*', based on the constructs of rehearsal, emotion control, attention control, and coping. The programme emphasises the constancy of change, and focuses on acquiring adaptive responses to make transitions in lifestyle.



Table 3.1

Maladaptive and adaptive coping

<u>MALADAPTIVE COPING</u>	<u>ADAPTIVE COPING</u>
EMOTIONAL	DETACHED
Feeling overpowered and helpless.	Not seeing situation or problem as a threat.
Becoming miserable, depressed and angry.	Keeping a sense of humour.
Taking frustrations out on others.	Seeing problem as separate from yourself.
Prepare for the worst possible outcome.	Resolve things by getting them into proportion.
AVOIDANCE	RATIONAL
Sitting tight and hoping it all goes away.	Use past experience to deal with situation.
Pretend there is nothing the matter.	Take action to change things.
Think about something else.	Take one step at a time , act logically.
Trust in fate, things will sort themselves out.	Give the situation full attention.

Table 3.2

The short and long-term consequences of coping styles

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<u>COPING STYLE</u>	<u>SHORT-TERM BENEFITS</u>	<u>LONG-TERM CONSEQUENCES</u>
MALADAPTIVE:		
Emotional coping	Expression of coping.	Increasingly overwhelmed by problem.
Avoidance coping	Temporary relief,blocked out.	Blocking out cannot be sustained.
ADAPTIVE:		
Detached coping	Able to stand back from issue.	Prevents over-identification with issue.
Rational coping	Logic determines resolution.	Problems put into perspective.

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To validate the programme, a group of students completed questionnaires addressing personality, life event and social support scales and also completed a health and social adjustment checklist immediately after entering university (Roger 1995). They were serially reviewed for 6 months and their health and adjustment status were categorised as worse, better or unchanged. A deteriorating health status was associated with emotional coping, rehearsal and negative life events. Based on his '*Challenge of Change*' programme Roger has defined stress in terms of "rehearsal in the emotion control model".

#### **3.4.4 Stress, life events and disease activity**

It seems reasonable to expect that relatively trivial daily stressors, that occur as part of everyday life, have lesser effects upon symptoms than do major life events, such as bereavement or divorce (Holmes and Rahe, 1967). Nevertheless, Delongis et al. (1982) argue that daily stressors, such as oversleeping, missing the bus or a phone incessantly ringing account for a larger percentage of total stress than major life events. Indeed, Garrett et al. (1990) in a prospective evaluation of 10 patients with Crohn's disease found that daily stressors had a much greater impact on physical symptoms, including faecal urgency, stool frequency and abdominal pain, than major life events. These authors were uncertain whether these symptoms were a psychological response to stress, increased symptom reporting owing to psychological effect of the stress, or both.

Gerbert (1980) criticised the studies which examined the association between major life events and physical symptoms in Crohn's disease. She concluded that such research has been hampered by methodological flaws, such as small sample size, bias of investigators, lack of control groups and use of differing data collection techniques which make comparison between studies extremely difficult. She identified the need for further investigation of the relationships between psychological variables and disease activity, and suggested that prospective studies be undertaken. These should include both physical and psychological components, incorporating life events and coping measures.

Mendeloff et al. (1970) conducted a large epidemiological survey in which the incidence of various social and cultural factors, thought to represent life stressors, were examined in 158 patients with ulcerative colitis, 102 IBS patients and 735 unselected subjects from the general population. The ulcerative colitis group and the general population had a similar incidence of life stressors, while the IBS group had a higher prevalence of stressful life events. The authors concluded that “either stress events are not important in the aetiology of ulcerative colitis or their effect is mediated by some other possibly constitutional factors in persons with this disease”.

This contrasts with the findings of Fava and Pavan (1977) who compared IBD patients to groups of patients with IBS or appendicitis, using the Paykel Life Events Questionnaire and reported a higher incidence of stressful events before the onset of ulcerative colitis patients than occurred in the appendicitis group. IBS patients reported more life events than either group. Paull and Hislop (1974) also reported that ulcerative colitis patients reported a significantly higher incidence of life crises occurring prior to the onset of symptoms in comparison to controls.

Duffy et al. (1991) prospectively examined major stress events in 124 IBD patients, and concluded that ‘stress-exposed’ patients demonstrated greater increase risk of disease relapse than ‘unexposed patients’.

In conclusion, studies show an association between daily life stress events and disease activity. The effect of major life events rather than minor events is difficult to ascertain. Major life events tend to occur less frequently in most

'normal' individuals, than in IBD patients and longitudinal studies need to be undertaken to address this.

### **3.5 Anxiety and Depression.**

Anxiety and depression are closely related and are often associated with stress. Anxiety has a tendency to be a reaction to stressful threats, and depression a reaction to stressful losses. A combined state of anxiety and depression is common.

#### *Anxiety*

As previously discussed, stress is a ubiquitous term with no universally accepted definition. It is commonplace for the term stress to be used interchangeably with anxiety or more particularly to describe anxiety as a reaction to stress. Moore and Burrows (1996) defined anxiety as a 'characteristic, unpleasant emotion induced by the anticipation of danger or frustration which threatens the security or homeostasis of the individual or the group to which he or she belongs'. Anxiety is associated with autonomic activation (fight or flight reaction), breathlessness, palpitations, chest or abdominal discomfort and diarrhoea.

Although both stress and anxiety may occur in response to an event, Endler and Parker (1990) suggested that this synonymous use is confusing and they differentiate between the constructs. In terms of diagnostic distinctions between the terms it is important to consider the criteria laid down by the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 1987a).

## *Depression*

The term depression covers a wide range of psychological disturbances. There is little confusion about the recognition of a severe state of depression, but milder degrees of the condition can be difficult to recognise. Wing et al. (1974) defined depressive states in terms of depressed mood, loss of interest, self depreciation, hopelessness, slowness, underactivity, inefficient thinking, poor concentration, suicidal plans or acts, morning depression, social withdrawal, guilt and observed depression. There are both emotional and physical aspects of these depressive states; the prime psychological symptom is lowering of mood with a persistent and prevailing sadness. The majority of available depression rating scales contain a diverse collection of symptoms, attitudes and feelings. Snaith (1987) warned that such rating scales would produce erroneously high prevalence rates and a large proportion of false positives if based upon case detection. Further criticism of psychological rating scales was made by Kutner et al. (1985) studying depression and anxiety in chronically ill dialysis patients. They found that the use of rating scales containing disease related items yielded exaggerated scores.

### **3.6 Measurement of psychological well-being**

The measurement of psychological morbidity is based on assessment of signs and symptoms of 'dysfunction'. There are numerous scales of psychological well-being; in particular those which are aimed specifically at detecting common psychiatric disorders, such as anxiety and depression. Gold standards

for psychiatric categorisation have been developed, such as DSM III. Psychiatric screening instruments are used to categorise psychiatric disease, but are not applicable to the research of health outcomes in patients without psychiatric disease. For the assessment of psychological morbidity in association with physical diseases, such as IBD, self-reported feelings of anxiety and depression, observed role functioning and behaviour are used. The next section highlights several of these psychological measurement tools and examines their relevance to the assessment of HRQOL.

*Hamilton Depression Scale* (HDS) is an observer rating scale, which includes assessment of cognitive and behavioural components of depression, with emphasis on assessment of somatic symptoms. The HDS, like many similar questionnaires cannot be used to establish a diagnosis of depression, but quantifies severity once depression has been detected. The HDS comprises twenty-one items including depressed mood, psychic anxiety, somatic anxiety, work, activities and gastro-intestinal symptoms. It is reported to have high concurrent validity and good agreement with the Beck Depression Inventory (BDI). Hamilton reported that the HDS has good inter-rater reliability and is applicable to both men and women (Hamilton, 1959; 1960).

The HDS has been used to measure psychological well-being in IBD. Scharff et al. (1989) compared 20 IBD patients to 45 irritable bowel syndrome patients. Using DSM III criteria as a comparison, they showed that IBS patients experienced higher levels of both anxiety and depression.

Bowling (1995a) noted the popularity of the HDS, but stated that it should be used with caution in patients with physical disease because of the high number of questions measuring physical symptoms.

*The Beck Depression Inventory* (BDI) was specifically designed to measure depression, and not both anxiety and depression as in many other psychological measurement tools. It was developed by measuring attitudes and symptoms in 409 depressed patients who were undergoing psychotherapy. A 21 item inventory based upon symptoms of depression, each with four Guttman-type responses was developed and validated. Guttman scales are cumulative and the respondent is required to endorse all the items less extreme than the one with which the individual agrees. This scaling method attempts to attain interval level measurement.

Symptoms and attitudes included in the BDI are sadness, pessimism, sense of failure, dissatisfaction, guilt, expectation of punishment, self-dislike, self-accusation, suicidal ideas, irritability, social withdrawal, indecisiveness, body image distortion, work retardation, insomnia, fatigability, anorexia, weight loss, somatic preoccupation and loss of libido. Reynolds and Gould (1981) devised a shorter 13 item version of the scale, which can be self or interview administered. There are numerous studies supporting the validity of the BDI. Beck et al. (1988) for example demonstrated that the concurrent validity of the BDI was high, showed it to be sensitive to the type of depression and could be used to distinguish depression from anxiety. Miller et al. (1985) reported good correlation between the HDS and the BDI. Schwab et al. (1967) described high



internal consistency in testing the reliability of the BDI. It should nevertheless be stressed that most testing has been conducted on psychiatric patient populations rather than upon normal volunteers or on groups of non-psychiatrically ill patients (Schwab et al. 1967). A comprehensive review of the reliability and validity of the BDI has been published by Beck (1988).

*The Symptoms of Anxiety and Depression Scale (SAD)*; assesses anxiety and depression by focusing exclusively on recent symptoms. SAD was devised by Bedford et al. (1976) and concerns seven states of anxiety and seven states of depression. There is limited work on the psychometric properties of the SAD and the questionnaire has been used predominantly in geriatric populations (Morgan et al. 1987). Bedford et al. demonstrated good predictive validity in tests involving 96 in-patients. They reported a significant association between depression scores and assessment by a consultant psychiatrist. The reliability of SAD has not been adequately studied and Bowling (1991) recommended more extensive testing before it can be applied to HRQOL measurement.

*The Hospital Anxiety and Depression Scale (HAD)* was developed by Zigmond and Snaith (1983) and provides a brief assessment of anxiety and depression. The scale was developed because the most widely used alternative HRQOL assessment tool, the General Health Questionnaire, is too lengthy and is unable to provide information about psychological disorders. Zigmond and Snaith highlighted two problems concerning questionnaires designed for the detection of mood disorders. Firstly, scores are affected by symptoms of physical illness, and secondly differentiation between anxiety and depression is difficult,

consequently they developed the HAD scale and this is now widely used in many disciplines.

The HAD scale comprises of 14 items on two-scales (7= anxiety, 7= depression). Replies relate to self assessment of subjective feelings in the preceding week and ratings are made on a 4-point scale, which measure the degree of psychological distress; none = 0, a little = 1, a lot =2 , unbearable = 3. Items are summed on the two sub-scales. The authors purposely excluded all items related to both emotional and physical disorder (e.g. headaches), and were based solely on the psychological symptoms of neurosis. Initial psychometric testing of HAD demonstrated good reliability and validity. Scores were not affected by the presence of physical illness, making the HAD scale extremely attractive in clinical research. Indeed, Fallowfield et al. (1990b) reported good levels of acceptability among general medical patients. In a study discussed earlier in this chapter, Andrews et al. (1987) tested the reliability and validity of the HAD scale as a screening method for detecting psychological morbidity in a group of 162 consecutive patients attending a clinic for IBD (91 had Crohn's disease, 71 had ulcerative colitis). DSM III, which is a clearly defined system for classifying psychiatric disorders based on diagnostic criteria was the standard against which the performance of the HAD was evaluated. Andrews et al (1987) reported that the HAD scale performed well in IBD patients, with excellent sensitivity and specificity. As a rating scale, the HAD compared favourably with both GHQ and BDI. The HAD scale is a popular

measurement tool in clinical research, due to its brevity, simplicity and the lack of influence by physical symptoms.

### *Summary*

Several scales have been used to measure psychological and psychiatric morbidity in IBD. The HDS is inappropriate for use in this patient population due to its emphasis on physical symptoms and the high number of items which concern somatic problems. The applicability of the SAD when addressing any other population group other than the elderly is unknown. The BDI has high validity and reliability but has been used predominantly in psychiatric populations and is dependent upon subjects' ability to accurately report their emotional (American Psychiatric Association 1987b). The literature suggests that HAD is the tool of choice in relation to IBD patients. Although Bowling (1995b) suggested the need for more work on its reliability and validity to be carried out before its performance as an indicator of psychological morbidity can be confidently judged.

### **3.7 Psychological treatment**

Although psychological factors do not cause IBD, it is clear that psychological factors do influence the natural history of the disease and psychological therapy may modify disease activity. In 1951, Groen and Bastiaans (1951) treated 29 ulcerative colitics using 'supportive psychotherapy', which they defined as "encouraging dependency on the therapist and allowing him to assume responsibility for certain aspects of the patients' lives". Over 1-9 years.

14 patients entered long-term remission, seven rated themselves as improved, and six had relapsed only after one year. Major limitations of this early study include the lack of a control group and lack of specificity of the intervention therapy.

Grace et al. (1954) examined a group of 34 ulcerative colitis patients who were treated by therapy termed 'superficial psychotherapy' which was aimed at alleviating stress. These patients were followed up for a period of two years and compared to a control group comprising IBS patients. Sixty-five percent of patients and 32% of controls improved. The retrospective nature of this study and the fact that patients were not randomly distributed are obvious methodological flaws.

O'Connor et al (1964) claimed beneficial effects of psychotherapy upon the course of the disease in 57 patients with ulcerative colitis. However, Rachman and Wilson (1980) discounted this study on the grounds that allocation to psychotherapy or control group was selective and that the two groups were significantly different prior to treatment .

Karush et al. (1968b) performed controlled studies in the 1960's. These were based upon 'psychotherapy of support and encouragement of dependency without attempts at insight'. They initially reported psychological improvement in five patients receiving therapy, defined as greater release of impounded anger and better life adjustment, whilst those patients receiving no support did not improve. Karush et al. (1977) performed more intensive studies in the 1970's. They reported that 57 patients who received psychotherapy, in addition to their

prescribed medical treatment had better physical and psychological health than matched controls who did not receive psychotherapy. Unfortunately patients were not randomly allocated to the active treatment or control group. Those who demonstrated psychological symptoms on pre-assessment were given psychotherapy and those without symptoms were assigned to medical treatment alone.

Freyberger et al. (1985) conducted six day trials of supportive psychotherapy involving inpatients with ulcerative colitis and Crohn's disease and reported significant decreases in levels of anxiety and depression in treated patients compared to a control group of similar hospitalised patients given only medical treatment. The authors did not report concurrent levels of physical symptoms and the extreme brevity of the intervention questions their conclusions.

Two nurse-led Canadian studies provide support for the role of stress management and relaxation therapy for IBD patients. Joachim (1983) assessed the effectiveness of deep abdominal breathing and massage on feelings of well-being in 14 out-patients with IBD. Active treatment apparently alleviated anxiety, reduced pain and insomnia. This study was uncontrolled and no effort was made to quantify specific IBD symptoms.

Milne et al. (1986) randomised 80 IBD patients to either a treatment group consisting of stress management classes, which included autogenics, personal planning skills and communication techniques or to routine follow-up. Subjects were followed up at four monthly intervals for one year. They reported a reduction in CDAI scores for those patients receiving treatment. Although the

study group and their controls were not matched for symptom severity at pre-treatment assessment, this study did clearly suggest that stress management techniques may have therapeutic value in the treatment of IBD.

Shaw and Ehrlich (1987) supported this conclusion in a study designed to measure the effect of relaxation therapy on chronic pain associated with ulcerative colitis. They randomised forty ulcerative colitis patients to receive a six week training in deep muscle relaxation therapy or routine follow-up. They found that the actively treated group recorded lower scores using the Zung Pain and Distress Questionnaire, reported fewer words on the McGill Pain Questionnaire and were taking significantly fewer anti-inflammatory drugs than the control subjects.

A slightly different approach to psychological intervention was taken by Taylor et al. (1993) who sought to determine which emotional states have a detrimental effect on the gut and whether the emotional concomitants of IBD can be reduced by a range of psychological interventions which were provided as an adjunct to medical therapy. The effectiveness of tutorial therapy, non-specific hypnotic relaxation and Whorwell's gut directed hypnotherapy over a twenty week period was studied. Nine of the ten studied patients experienced a reduction of emotional symptoms and physical symptoms improved in six patients (Whorwell et al. 1984). Gut directed hypnosis was most effective in reducing physical symptoms and cognitive therapy was more effective in the relief of emotional symptoms. Taylor et al. concluded that psychological therapies may be of benefit to IBD sufferers. Clearly this conclusion was based

upon an extremely small sample size, with a very short follow-up period prompting a rather damning review from Heap (1994).

Despite these criticisms, Taylor argued in favour of gut directed hypnotherapy; a process whereby hypnotised patients undergo ego strengthening suggestions, followed by laying on of hands to induce feelings of warmth and control of abdominal symptoms. This is followed by suggestions of symptom reduction and personal control over gut function which is reinforced with visual imagery. This form of therapy has been shown to be effective in the treatment of IBS, but its applicability to the treatment of IBD remains unknown (Taylor, 1994; Whorwell et al. 1987).

### *Summary*

In the examination of studies undertaken to determine the impact of psychological treatments in IBD there are many positive findings which have emerged to warrant a strong case for psychological treatment in IBD. In a review of the literature, Gerbert (1980) concluded that there is a strong suggestion of an association between psychopathology, stressful life events, personality and IBD.

In a review of the overall effects of psychological therapy, Rachman and Wilson found modest evidence to support the view that specific psychological therapy can produce beneficial changes. They discounted two studies (O'Connor et al. 1964; Karush et al. 1968a), discussed in this chapter addressing the effects of psychotherapy in ulcerative colitis and concluded; "It is not implausible that supplementary psychological help may facilitate recovery from this disorder, but

the evidence is inadequate and cannot support unequivocal claims of success” (Rachman and Wilson, 1980).

Older studies of psychological treatments for IBD are methodologically inadequate and prospective, controlled studies involving larger numbers of patients are required. Shwarz and Blanchard (1990) for instance advocate large-scale controlled studies in which IBD patients record symptoms, psychological state, and life events are recorded over a prolonged period of time. They highlight the importance of assessment of both the psychological distress variables and the disease status variables and the need to incorporate coping strategy education within psychological treatment programmes.



## **CHAPTER FOUR**

### **INTRODUCTION TO COUNSELLING**

## **4.1 Introduction**

What is a counselling relationship ? This question is frequently asked by health professionals involved in caring relationships, or perhaps more specifically the question asked might be 'Am I helping or am I counselling ?'. There are many people who provide 'non-professional counselling' in relation to the human services professions of nursing, teaching, clergy and the police.

Although the theory of counselling within the nursing profession is widely acknowledged, the practice of counselling and its implications are a different matter. In specialities such as psychiatry, care of the dying, oncology and in recent years HIV/AIDS medicine, the role of the nurse as a counsellor is well developed (Howe, 1989). There is a perception that the role of the nurse as a counsellor may not be as well received in the general medical clinical setting. The nursing literature suggests that most nursing time is devoted to physical as opposed to psychological care (Peterson, 1988). When nurse/patient contact is reduced to the absolute minimum and where human values seem to be marginalised, as is often the case in general medicine, counselling and the practice of counselling skills are tolerated but not generally encouraged. Therefore the meaning and the place of counselling in nursing practice varies widely in different clinical settings and in many areas is still evolving (MacLeod Clark, 1988).

#### **4.1.1 Definitions of counselling**

A dictionary will define counselling as “giving counsel or advice”, or “making recommendations”. Within the nursing profession, Nurse (1975) views counselling as ‘a dialogue in which one person helps another who has some difficulty that is important to him or her’, which for many nurses is an integral part of their work. These definitions are considered by those involved in counselling as inadequate and even contrary to practice.

The national professional counselling body, The British Association for Counselling (BAC), have frequently rewritten their definition. Most recently their Code of Ethics and Practice for Counsellors (BAC, 1993) describes the nature of counselling in the following way;

“The overall aim of counselling is to provide an opportunity for the client to work towards living in a more satisfying and resourceful way. The term ‘counselling’ includes work with individuals, pairs or groups of people, often, but not always, referred to as ‘clients’. The objectives of particular counselling relationships will vary according to the clients needs. Counselling may be concerned with developmental issues, addressing and resolving specific problems, making decisions, coping with crisis, developing insight and knowledge, working through feelings of inner conflict or improving relationships with others. The counsellor’s role is to facilitate the client’s work in ways which respect the client’s values, personal resources and capacity for self-determination.

Only when both the user and the recipient agree to enter into a counselling relationship does it become 'counselling' rather than the use of 'counselling skills'.

It is not possible to make a generally accepted distinction between counselling and psychotherapy. Some use the terms interchangeably whilst others distinguish them. Regardless of the theoretical approaches preferred by individual counsellors, there are issues which are common to all counselling situations”.

It is probably not helpful to draw such rigid lines of professional demarcation which can prevent professionals, such as nurses, from providing a counselling service to their patients without formal accreditation by a professional counselling body. It is clear that many nurses in their everyday work fulfil many of the criteria that constitute counselling; however in this thesis emphasis is placed on the use of counselling skills within a helping relationship. The Code of Ethics and Practice for Council Skills (BAC, 1989) of the BAC states that:

“The term ‘counselling skills’ does not have a single definition which is universally accepted. For the purpose of this code, ‘counselling skills’ are distinguished from ‘listening skills’ and from ‘counselling’. Although the distinction is not always a clear one, because the term ‘counselling skills’ contains elements of these two activities, it has its own place in the continuum between them. What distinguishes the use of counselling skills from these others activities are the intentions of the user, which is to enhance the performance of their functional role, as a line manager, nurse, tutor, social

worker, personnel officer or voluntary worker. The recipient will, in turn, perceive them in that role.

To define the nursing role in counselling the following questions should be asked:

a) Are you using counselling skills to enhance your communication with someone but without taking on the role of their counsellor ?

b) Does the recipient perceive you as acting within your professional/caring role (which is not that of being their counsellor )?

(i) If the answer is YES to both of these questions, you are using counselling skills in your functional role.

(ii) If the answer is NO to both, you are counselling.

(iii) If the answer is YES to one and NO to the other, you have a conflict of expectations and should resolve it.

Only when both the user and the recipient explicitly contract to enter into a counselling relationship does it cease to be 'using counselling skills' and becomes 'counselling'".

The BAC therefore see the basic difference between the use of counselling skills and counselling as a contract that is drawn up between the helper and the client. Although it is the nurse/patient relationship that is primarily explored in this study, this relationship will be frequently be termed counsellor/client, in line with the BAC definition. This is to underline that this study addresses the use of a range counselling skills by a nurse practitioner in the management of psychosocial morbidity, as opposed to practising counselling in the purest sense

as defined by the BAC. However it is not possible to provide such a counselling support service without first addressing the process of counselling itself, as there are some basic elements that are common to both situations.

## **4.2 Effectiveness of Counselling**

Before considering the effect of counselling in the context of general health care it is appropriate to first examine the literature evaluating counselling, which for the purpose of analysis is generally included within the field of psychological therapy. Apart from Masson's (1989) recent critique of psychotherapy in which he cites numerous examples of dubious practice to support his accusation that psychotherapy is a manipulative and corrupt practice. Eysenck (1952) provided one of the earliest reviews of psychotherapy and concluded that there was no evidence for the effectiveness of psychotherapy or counselling in comparison with untreated controls. This review was subject to critical appraisal by Bergin and Lambert (1994), who implied that Eysenck was more concerned about advocating a behavioural approach towards psychotherapy than with the evaluation of psychotherapy. Indeed, Eysenck (1994) proclaimed the scientific efficacy of behavioural therapy and decried the theory and application of psychotherapy as unscientific. Eysenck (1994) examined the impact of psychological intervention in the treatment of psychosomatic disease, and serious illnesses like cancer and coronary heart disease. He cited evidence for the value of behaviouristic psychological treatment methods for prophylaxis, and for prolongation of life in cases of incurable disease. Further to these findings

Grossarth-Maticek and Eysenck (1991) proposed that psychotherapy had marked negative effects on a similar study group.

Hans Strupp (1982) vigorously set forth his views that psychotherapy most certainly is scientific, stating 'What sets psychotherapy apart from other forms of psychological healing- and of course medicine- is the planful and systematic application of psychological principles, concerning whose character and effects we are committed to become explicit'.

A favourable review of psychotherapeutic intervention was provided by Luborsky et al. (1975) who found considerable support for the effectiveness of psychotherapy in their review of 40 studies and suggested a verdict similar to the Dodo bird in Alice in Wonderland : 'Everyone has won and all must have prizes'. They concluded that 'most comparative studies of different forms of psychotherapy found insignificant differences in proportions of patients who improved by the end of psychotherapy' (p1003). Smith and Glass (1977) were concerned about the number of studies included in their review and maintained the "the number of studies in which the effects of psychotherapy and counselling have been tested is closer to 400 than 40" (p752). Rachman and Wilson (1980) were also critical that methodological quality was not an important factor in the inclusion of studies of psychotherapy and that their conclusions were drawn without reference to accepted comparative statistical techniques.

Although a vast amount of research has been conducted examining the effectiveness of psychotherapy, overall results are inconclusive and in some cases self-contradictory. Orlinsky (1989) believed that these findings may be partially

related to the problem that researchers have in coming to terms with what precisely counselling and psychotherapy are: forms of treatment, education, social control or ritual and redemption ?

#### **4.2.1 Effect size and outcome evaluation**

The notion that psychotherapy is effective and that there are no significant differences between alternative treatment approaches has also been registered by Smith and Glass (1977) who do not disguise their views on the efficacy of counselling and psychotherapy and addressed comparative outcome research with meta-analytic reviews. Meta-analysis is a procedure that statistically analyses a large number of studies. The basic unit of analysis is 'effect size' which is defined as the mean difference between the treated and control subjects divided by the standard deviation of the control group.

Smith et al. (1980) published the results of their meta-analysis of 475 psychotherapy research studies, which by their definition of psychotherapy included counselling studies and calculated a mean effect size of 0.85 which they took to indicate that the average patient treated by psychotherapy is better than 80% of untreated controls at the end of intervention and that there was little evidence of negative effects from psychotherapeutic intervention, or that any one specific type of therapy was superior. Measures of anxiety and fear were particularly prone to show improvements within the studies under question.

Rachman and Wilson (1980) stated that, ideally, there should be a place for meta-analytic evaluations of groups of psychotherapeutic studies and that therapy outcome research is very far from a point where such a strategy is



appropriate. They criticised Smith and Glass's disregard for methodological quality of therapy outcome research which is exemplified by their overall acceptance of Luborsky et al.'s review as evidence for the efficacy of psychotherapy. Lambert et al. (1986) were critical of Smith and Glass's meta-analytical review in its dependence on cross-study comparisons in which, for instance, comparison of behaviour therapy in one study was compared with verbal therapy in another. These authors claimed that there is now little doubt that psychological treatments are generally beneficial, although it remains equally true that not everyone benefits to a satisfactory degree.

#### **4.2.2 Power analysis**

Kazdin and Bass (1989) postulated the fact that comparative studies of psychotherapy often find few or no differences in the outcomes of alternative treatments. As a rule, studies are insufficiently powerful to detect the sorts of effects sizes likely to be found when two or more treatments are contrasted. Power calculations are commonly made on the basis of non-treatment against treatment which may not be sufficient for the comparison of two treatments. Kazdin and Bass (1989) evaluated the power of the treatment outcome studies in psychotherapy to detect differences when alternative treatments are compared. Power was defined as a function of the criterion for statistical significance, sample size and the difference that exists between groups (effect size). Eighty-five outcome studies were examined, over a three year period, to provide estimates of effect sizes and then to evaluate statistical power at post-treatment and follow-up. Their findings indicated that the power of studies to detect

differences between treatment and non-treatment is generally adequate given the relatively large effect sizes usually evident for this comparison. Conversely, power may be relatively weak to detect the small to medium effect sizes likely to be evident when alternative treatments are contrasted with each other. They concluded that neglect of power could have major implications for interpretation of psychotherapy outcome studies.

#### **4.3 Counselling in Health Care**

Davis and Fallowfield (1991) questioned whether counselling can be shown by research to be beneficial in the health care context. Martin (1988) believed that in the area of general practice, when resources are scarce, the widespread adoption of counselling is unwise without first establishing its effectiveness.

Discussion on the use of counselling within general practice was summarised by Wyld (1981) who said despite the absence of controlled experimentation, that numerous advantages had been demonstrated by counsellors. Watson (1983) reviewed the area of psychological intervention for patients with cancer and concluded that there was evidence that counselling was beneficial. However, she remained cautious as a result of the lack of research and the difficulties in comparing available studies. East (1995) concluded that evaluative studies of the effectiveness of counselling in medical settings are essential to identify which patients might benefit most from counselling and also to ascertain levels of skills, competence and expertise required by counsellors within the medical setting.

#### 4.3.1 Nursing and Counselling

There has been considerable interest in the extent to which counselling skills should play a part in the nursing role. The United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) which defines standards of training introduced *Project 200: a new preparation for practice (1986)* (United Kingdom Central Council for Nursing, 1986), a new preparatory course for all nursing students. This includes a module on counselling skills within the course curriculum and opportunities for further counselling training within the specialised vocational areas. East (1995) believes the introduction of Project 2000 to be a significant change in the attitude and the approach of nurse education towards counselling. Prior to its establishment she felt that nursing staff might have displayed varying degrees of sensitivity and insight into their patients' feelings but counselling was not a word commonly used in the medical profession, until relatively recently.

The nature and emphasis placed upon counselling varies greatly between clinical specialities. It is clear from the developing literature addressing the topic of counselling within the speciality of HIV/AIDS medicine that this particular issue is one of growing concern to health care professionals in the United Kingdom, however it could be argued that the same principles apply to the use of counselling skills for all health related problems (Hopper et al. 1991).

The issue of effectiveness of counselling in IBD has not been fully addressed. However, Watson et al. (1988) evaluated the work of nurse counsellors in relation to early cancer, addressing the provision of emotional support and

information before and after mastectomy. They believed counselling to be beneficial in speeding up the process of adaptation to illness, these findings endorsed earlier findings on the effectiveness of nurse counsellors in the care of early cancer carried out by Maguire et al. (1982).

In conclusion, counselling may be undertaken by nurses as part of a consistent theoretical framework. This is because the nurse must understand that everyone carries a certain set of beliefs about their psychological make-up and that these beliefs can vary greatly between individuals. An understanding of the main psychological approaches to counselling is of paramount importance to any nurse engaged in a helping relationship. In conjunction with a basic knowledge of human nature and illness, the nurse must adopt one or several of these psychological approaches to gain insight into their patients and this process is fundamental to the effective use of counselling skills.

#### **4.4 Effectiveness of 'non-professional' counselling.**

The use of nurses and other non-professional counsellors in one-to-one work has attracted controversy in recent years, following publications assessing the therapeutic effectiveness of non-professional counsellors skills. Durlak (1979) in his review of forty-two American studies reported that the research indicated that non-professional counsellors, such as nurses and teachers tended to be more effective than trained professional counsellors. He listed several contributory factors which might explain why non-professionals using counselling skills should achieve good results and these are shown in Table 4.1.

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Table 4.1

Factors which explain the benefits of 'non-professional' counselling

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They are perceived by clients as more "genuine" than professional counsellors.

They are less likely to apply professional labels to clients.

Non-professionals restrict themselves to straightforward safe interventions.

Patients or clients will attribute success and progress to themselves rather than to their helper.

'Non-professional counsellors' are able to refer difficult cases on to professionals.

The non-professional helpers are more highly motivated to help than their professional colleagues.

They are able to give more time to clients.

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Durlak's (1981) findings are relevant to the nurse who has no formal professional counselling training but is working within a caring relationship. Nevertheless, his findings provoked a strong reaction, specifically from Nietzel and Fisher (1981), who regarded his study as using inappropriate definitions of 'non-professional' and having inadequate internal validity. Despite these criticisms recent literature supports Durlak's original findings, concluding that lay professionals were in many cases more effective than trained therapists (Hattie et al. 1984). Berman and Notman (1985), using more rigorous criteria for accepting studies as methodologically adequate, concluded that there were no overall differences in effectiveness between professional and non-professional

therapists. Perhaps the most comprehensive research comparing the effectiveness of professional and non-professional counselling was undertaken by Strupp and Hadley (1979). Distressed students who were experiencing feelings of anxiety and isolation at an American college were randomly allocated to support from an experienced counsellor or support from a member of college staff who held no professional counselling training. These were selected on the basis of a reputation for trustworthiness and interest in their students. The styles adapted by the two sets of helpers differed markedly but both groups of students showed similar improvement in psychological well-being. It was concluded that non-professionals using counselling skills in a helping relationship can achieve a great deal through the effects of a benign human relationship. Although this conclusion was secure, it also highlighted several areas where non-professional counsellors were deemed less well equipped to deal adequately with specific dilemmas and difficult cases such as organic mental illness and the management of individuals with clinical depression (Gomez-Schwartz and Schwartz, 1978).

Although the general trend in these studies may suggest that years of professional counselling training is valueless, it is necessary to be cautious when interpreting their findings. The studies in question covered a wide range of groups including psychiatric patients, student populations and people in crisis. Few studies have examined the effectiveness of non-professional counsellors, such as nurses, when dealing with chronic physical illness.

Godber and Mayberry (1988b) examined the role of lay counselling amongst twenty-five patients with IBD in Nottingham. However, no attempt was made to

assess the outcome of counselling in this patient group, rather to document those areas and topics in which counsellors would require further training, these are shown in Table 4.2. Regardless of the fact that no objective evaluation was undertaken, they encouraged the use of lay counselling support in the management of IBD.

Table 4.2

Topics discussed with lay counsellors

Problems discussed	No. (n=25)
Need to talk to someone who understands the problems of IBD.	18
Lack of confidence in doctor due to lack of interest in patients' problems.	10
Too embarrassed to tell friends about their disease or its problems.	8
Diet	3
Employment	3
Financial difficulties	1
Medical queries (all referred back to family doctor)	4

**4.5 Psychological approaches to counselling**

**4.5.1 Psychodynamic approach**

Sigmund Freud (1949) is usually viewed as the father of the psychodynamic school of psychology. Freud structured our mental apparatus into three systems: the id, the ego and the super-ego. Psychological well-being depends on the

optimum inter-relationship between these three systems (Freud, 1973). In Freud's view people are, to a greater or to a lesser extent, affected by unconscious motives or drives. The unconscious level of mind is influenced by experiences that happened to us in earlier parts of our lives that we were unable to deal with at the time. When we encounter an experience in the present that is in any way similar to that past event, we experience anxiety, because we are unconsciously reminded of the situation. For many psychodynamic psychologists, the key to understanding current behaviour is through a thorough exploration of the past. Thus the psychodynamically orientated counsellor will usually choose to explore the client's past history and help him or her to identify and, if necessary, to relive painful past events in order to make the person less anxious and more able to make rational decisions about the present. Counselling skills based upon the psychodynamic approach involve the patient highlighting the relationship between past and present life events and then examines unconscious forces which may influence behaviour. It also allows for the expression of pent up emotion. The psychodynamic approach when applied within a helping relationship has been reported to be effective in alleviating anxiety (Hall, 1954).

#### **4.5.2 Behavioural approach**

Behaviourists use a more objective approach to the study of human behaviour. Murphy and Kovach (1972) summarises this by stating "that if all human behaviour is learned, it can therefore, if necessary, be unlearned". Such a theory evolved through the process of positive reinforcement, that is, we learn those



behaviours that we are encouraged to learn and forget those for which no encouragement is forthcoming. The important issue is not the recollection of painful past events, but the identification of what the patient sees as desirable behaviours. Positive behaviours are encouraged and no effort is made to try to understand the underlying cause of behaviours in relation to the past. The key issues in this behaviourist approach are therefore learning, unlearning and relearning (Ellis, 1973). The behavioural approach allows for the setting of practical aims and objectives in counselling and identify practical programmes of small changes that the client will be able to achieve in order to cope with problems of living.

#### **4.5.3 Humanistic approach**

Humanistic psychology draws heavily on the field of existential philosophy (Shaffer, 1978) and is based upon the view that people are essentially free and responsible for their own condition. It challenges the determinism of psychodynamic and behavioural psychology and therefore it dismisses the view that we are driven by an unconscious mind or that we are a product of a range of learnt behaviours.

The humanist argues that consciousness gives us the ability to determine our own course of action through life and that we are the best arbiters of what is and is not good for us (Rogers, 1951a). Humanistic psychology states that there is no plan of how our minds work or how their behaviour could be manipulated. Humanistic psychology stresses individuality and individual differences in the human condition.

It is from this humanistic school that Carl Rogers developed his client-centred approach to counselling (Rogers, 1959b). He argued that an effective counselling relationship is based upon trusting the client's ability to find his or her own way through their problems.

The aim of counselling for Rogers was not necessarily to explore the person's past, nor to modify their behaviour but to accept them for what they are and to help them progress through their difficulties by their own route (Rogers, 1959a). Therefore counsellors using this humanistic approach are not experts in other people's problems but individuals who accompany other people on their search for answers to personal problems. This client-centred approach has many advocates in the counselling world, it provides the basis of a great deal of the nursing theory related to counselling and is the starting block for counselling support in many patient based self help groups such as the National Association for Crohn's disease and ulcerative colitis (MacLeod et al. 1991).

However, health care provision has changed dramatically in the 1990's with changes in individual's financial, work and life situations. These changes have contributed to a considerable debate about the use of the time consuming client-centred approach to a counselling relationship. Writing on recent developments in humanistic psychology related to counselling, Dryden et al. (1989) stated; "The object of person-centred counselling...is to help the client 'to become what he or she is capable of becoming' (Rogers, 1951). This is defined by Maslow as the achievement of self-actualisation (Rogers, 1951b; Maslow, 1962). These terms have a slightly hollow ring about them in the enterprise economy of the

late 1980's and early 1990's of Britain, in which the division between the 'haves' and the 'have nots' is increasingly apparent. Striving for self-actualisation is easier if one is well-off, well-housed, has a rewarding and secure job and lives in a pleasant environment. It is much more difficult for the unemployed, poor, ill-housed, and socially disadvantaged. Terms like self-actualisation simply do not feature in and do not derive from the culture of the 1980's (Dryden et al. 1989). Howard (1990) expanded this theory and suggested that those employing counselling skills shed their naivety and the 'syrupy' illusions of Rogers and his many cohorts. Murgatroyd and Woolfe (1982) note that in recent years approaches towards counselling and caring for people with different problems of living are changing. They see a movement away from the client-centred approaches of Rogers towards an interest in short-term, crisis-orientated counselling for which more directive, action-orientated procedures are advocated. Farrelly and Brandsma (1974) see a departure from the traditional client-centred approach to counselling associated with a move towards a more confrontational and challenging counselling process.

They propose four 'challenge-related hypotheses' within a counselling relationship;

- 1) Clients can change if they choose.
- 2) Clients have more resources for managing problems in living and developing opportunities than they or most helpers assume.
- 3) The psychological fragility of clients is overrated both by themselves and others.

4) Maladaptive and antisocial attitudes and behaviours of clients can be significantly altered no matter what the degree of severity or chronicity.

In a similar vein, it is suggested that action and challenge are an essential part of human make-up and that people have a 'bias towards action'. Howard et al. (1987) suggested that clients move, directly or indirectly, to one of five states:

- 1) change from a passive to a more active state;
- 2) change from a state of dependency on others to relative independence;
- 3) change from a present orientated time perspective to a perspective encompassing past, present and future;
- 4) change from solely subordinate relationships with others to relationships as equals or superiors;
- 5) change from lack of a clear sense of self to a clearer sense of self and control of self.

Despite the criticisms and limitations illustrated, the client-centred approach continues to be a widely used and practical framework for the basis of many counselling relationships.

#### **4.5.4. Cognitive approach**

The cognitive approach is based on the principle that what we think about ourselves affects the way we feel about ourselves and if we change our way of thinking we can modify our feelings. Consequently many people have exaggerated or incorrect beliefs about themselves that affects their self-image. For example patients with active IBD may make statements such as “I am a burden to everyone” or “things will never improve” or “I am completely useless in this state”. These general statements can have a negative effect on performance and lifestyle.

The aim of the cognitive approach is to challenge inaccurate and negative statements in order to modify personal perception. This style of counselling may be challenging and confronts the client’s belief system. In some respects, this cognitive approach opposes the style of counselling advocated by Carl Rogers, although the client-centred approach provides the theoretical basis for establishment of a helping relationship.

Cognitive counselling (commonly referred to as therapy) was initially developed in the early 1960’s by Beck (1991) . It takes an information-processing approach to clients based on the premise that the way people interpret their experience determines the way that they feel and act. Beck developed several cognitive models for the treatment of depression, anxiety disorders, distressed couple relationships and personality disorders. The main goal of Beck’s cognitive counselling is to re-energise the client’s reality testing system.

Meichenbaum (1986) is associated with the issue of metacognition in counselling and therapy. This is a cognitive-behavioural approach to therapy and refers to the ability of people to reflect on their own cognitive processes, to be aware of how they are going about thinking about something , or trying to solve a problem. Meichenbaum referred to the cognitive content of his therapy as self-talk or internal dialogue. Self-talk has two main functions; coaching and calming, and refers to how people talk to themselves before, during and after difficult situations.

Albert Ellis (1977) who developed 'Rational Emotive Therapy', an offshoot of cognitive therapy, argued that there are twelve typical irrational beliefs that people may hold about themselves. This list, presented in Table 4.3 was not intended to be exhaustive, but it does represent commonly held erroneous beliefs that may have a profound effect on how a person thinks, feels and acts.

Ellis (1973) claimed that anyone who holds any one or more of these beliefs is likely to experience distress inasmuch as they influence the way that person acts.

The cognitive approach to counselling is best implemented in relationships where the client relies less on personal warmth and more on confrontation in the counselling relationship, to employ a logical and rational approach to problem solving and to encourage rational thinking in someone who is highly emotional.

The cognitive approach has been used effectively with people who suffer from depression and other debilitating problems in living as it teaches these clients how to effectively evaluate and modify their thinking.

#### **4.5.5. Transactional Analysis approach**

Transactional analysis was formulated by the American psychotherapist Eric Berne (1972) who provides an economical way of describing and discussing people's relationships with one another. The analysis suggests that we relate to others from three distinct 'ego states', namely the Parent, the Adult and the Child. When we operate from the parent (which is developed through the early absorption of parental and judgmental attitudes), we tend to talk down to others, feel superior to them or patronise them.

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Table 4.3

Irrational beliefs people hold about themselves

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- 1) It is a dire necessity that I be loved or approved of by everyone for everything I do.
  - 2) Certain acts are wrong and evil and those who perform those acts should be severely punished.
  - 3) It is terrible, horrible and catastrophic when things are not the way I would like them to be.
  - 4) Unhappiness is caused by external events-forced upon me by external events, other people and circumstances.
  - 5) If something is or may be dangerous or fearsome, I should be terribly concerned about it.
  - 6) It is easier to avoid or replace life's difficulties than to face up to them.
  - 7) I need someone or something greater than myself upon whom or which I can rely.
  - 8) I should be thoroughly competent ,adequate and achieving in all the things I do and should be recognised as such.
  - 9) Because something in my past strongly affected my life, it should indefinitely affect it.
  - 10) What people do is vitally important to my existence and I should therefore make great efforts to change them to be more like the people I would like them to be.
  - 11) Human happiness can be achieved by inertia and inaction.
  - 12) I have virtually no control over my emotions and I just cannot help feeling certain things.
-



On the other hand, when we operate from the child (which is mainly developed through our experiences as a child) we tend to adopt a subservient relationship with regard to other people. Thus we can become too dependent on them, and submit too readily to their demands and we feel uncomfortable as a result. Berne (1964) argues that the most appropriate method of relating to others is through the adult, in which we relate to others as mature equal beings.

Beyond this first formulation, it is possible to map the ways people relate to one another from ego state to ego state. The chronically physically ill patient may well have related to their partner on an adult-to-adult basis when their disease was inactive, but during a period of illness their partner may become overprotective and the patient is addressed as a child. This represents what Berne calls 'crossed transaction' and can be a source of difficulty within a relationship. The aim of transactional analysis is to enable clients to identify these relationship 'games' and to learn how to communicate more readily on an adult to adult basis. This approach to counselling enables clients to identify more adult ways of dealing with problems and encourages assertiveness and helps deal with marital and relationship difficulties.

#### **4.5.6 Eclectic approach**

It is argued by many counselling theorists that no single psychological theoretical approach to counselling can be appropriate for every counselling situation. This may be particularly true when addressing psychological morbidity within a group of chronically ill patients (such as those with IBD), particularly when the disease varies in severity and symptomology and patients have differing levels of social

support, social backgrounds, cultures, personal experiences and personality traits.

It is therefore appropriate to adopt an eclectic approach to the use of counselling skills in which the most appropriate and practicable techniques have been selected from the range of possible approaches. Garfield and Krutz (1977) saw that the most common reason for adopting an eclectic approach was to allow for 'whatever theory or method that seems best for the client'. Nelson-Jones (1982) viewed this process of integration of different theoretical positions as achievable through the identification of common elements or threads across theories. For example virtually all the theorists cite effective thinking as a counselling goal, whether it is called rationality (Ellis and Rogers), acceptance of reality and responsibility, (Glasser), an effective Adult, (Berne) or a strong ego (Freud). The eclectic approach allows for the development of a personal repertoire or personal style, and a flexible approach towards the use of counselling skills. The application of this approach in health care practice helps the individual who has very varied problems in living (Burnard, 1994a). In support of a eclectic approach, Allport wrote (1962) 'The trouble with our current theories of learning is not so much that they are wrong, but they are partial', and the same may be said about the various psychological theories of counselling. For example, the person centred approach has its focus on capacity for experiencing, the humanistic rational approaches have a major focus on thinking, and the traditional behaviourists have their major focus on acting. Individuals counselling or using counselling skills within a helping relationship must always remember

that they are dealing with the “whole” individual who needs to be able to experience, think, and act effectively.

#### **4.5.7 Conclusion**

This is by no means an exhaustive review of the main theories of counselling; indeed there are many other theories that have not been addressed in this chapter as they are less practical within the health care setting. Psychological approaches based upon sound principles provide the nurse counsellor with a theoretical framework from which to understand the needs of the individual and to provide a sound background for their practice. Carkhuff (1969) describes the concept of stages in counselling within these theoretical psychological approaches based on a stage model of client development and related counsellor interventions. The use of such helping models provide a practical and structured basis to counselling.

#### **4.6 Models of Helping**

No two counselling relationships can ever be the same. Counsellors and clients usually come from different backgrounds and have different life experiences. Counselling skills, when used appropriately, can make the difference between more misery or a way ahead to a client. The use of these skills is therefore an active process, which can be likened to a journey. Tschudin (1995b) viewed such a helping journey as far easier when you know where you want to go and you have a plan of how to get there; helping models provide such a framework.

Models act as a practical method of structuring the counselling process and are a means of evaluating the process as it develops. Burnard (1994b) compares the use of models of counselling to that of a geographical map which can greatly aid and help explore the relationship between the client and the counsellor. Like any map the helping relationship is never the same as the territory itself and a helping model may never match exactly what happens in the relationship but it does provide a different means of helping another person to make a journey confidently and under his or her own steam.

The range of available of validated helping models are all fairly similar, but not quite the same. When using a model or framework, and when both the helper and the client provide the structure of the model, the work will be more focused, more satisfying, and goals may be identified and achieved more quickly. Models are also useful to keep tasks in hand in a relationship and as a reference point when 'stuck' or 'lost' during a conversation in order to find new perspectives. Nelson-Jones (1993a) stated that models have to be basic and simple to

understand; he found that the use of the acronym DASIE (see below) for his model helped individuals to remember the separate stages, this further developed in Table 4.5.

**D DEVELOP** the relationship, identify and clarify problem (s).

**A ASSESS** problem(s) and redefine in skills terms.

**S STATE** working goals and plan interventions.

**I INTERVENE** to develop self-helping skills.

**E END** and consolidate self-helping skills.

At this stage it is of use to compare these helping models to the four stages of the nursing process defined as assessment, planning, implementation and evaluation. There are obvious comparisons that can be made between the structure of nursing process and helping models. The major difference relates to the fact that helping models are directed towards problem management, whereas the nursing process is orientated towards problem solving. This may be difficult for many nurses to accept as, on the whole, nurses are educated to be problem solvers; they see a specific problem, identify it and set out to resolve it. In contrast for counselling skills the focus is placed firmly with the individual rather than the problem.

The patient with IBD may present with a problem such as faecal urgency but this problem would not be the focus of the relationship. If it were, then the process used is either advising or information giving. A problem has a solution. counselling works towards a goal. Counselling helps the person and that means

the nurse counsellor focuses on the IBD patient's feelings first of all and then on the meaning of these feelings for the person.

An overview of the recognised models of helping relationships will help highlight the similarities between models which are by no means mutually exclusive in their application. A combination of models can be applied to aid counselling skills.

#### **4.6.1 Carkhuff's Model of Helping**

Carkhuff (1987b) called his theoretical approach a 'developmental model for helping'. His basic premise is that 'to live is to grow'. Depending on what we can do for ourselves, what others do for us, or what we do for others at crisis points in life is 'for better or for worse' according to Carkhuff. He stated three goals for helping; exploration, understanding and action. These combine in a process which recycles itself. Through action comes feedback, which leads to further exploration and in turn sets the stage for more accurate self-understanding. In this setting Carkhuff introduces his four stages of helping: attending, responding, personalising the experience and initiating action (Table 4.4). Carkhuff's (1979) model aims to provide the outline of a helping relationship through these four steps.

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Table 4.4

Carkhuff's Four Stages of Helping

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- 1) Attending relates to being with the client both physically and psychologically, attending both verbally and non-verbally. The key ingredient of attending is listening.
  - 2) Responding; means hearing the clients words, but also being aware of behaviour and feelings.
  - 3) Personalising the experience is making the step from 'it happened because of ...' to 'it happened because I...'. When individuals are able to take responsibility for actions and feelings they will be more able to change because arbitrary forces are no longer working on them they themselves will make things happen.
  - 4) Initiating action is the goal and also the first step along a new and different way of being.
- 

**4.6.2 Nelson-Jones Model of Helping**

Nelson-Jones (1993a) described a "Lifeskills Helping Model" in which helper and client collaborate to attain life goals. Each stage of his model involves the use of both 'thinking skills' and 'action skills' for both the helper and the client. Thinking skills include areas such as perceiving accurately, coping self-talk, possessing realistic personal rules and attributing cause accurately. Thinking skills can be used to influence feeling as well as to guide action. Unlike thinking skills which are mostly covert, action skills are by definition overt. The appropriateness of action skills differs across areas of living: for example

relationships, sex, work, study or leisure. The distinction between thinking and actions skills is basic to the lifeskills model of helping in Table 4.5:

Nelson-Jones (1993b) uses the term 'lifeskills helping'. He thinks of people as possessing skills strengths or skills weaknesses rather than having skills or not having them. He draws his philosophy together into a definition of lifeskills:

"Lifeskills are personally responsible sequences of self helping choices in specific psychological skills areas conducive to mental wellness. People require a repertoire of lifeskills according to their developmental tasks and specific problems of living".

Nelson-Jones states that his DASIE five stage model is not only for managing problems. The model also assumes that where possible helpers will work with underlying skill weaknesses will help clients solve further problems. Thus DAISE is a model of managing problems and altering unfavourable lifeskills.

#### **4.6.3 Egan's Model of Helping**

Egan describes an eclectic "open systems model" which is a problem-management/opportunity-development approach to helping. This involves a three stage model of helping. These steps combine for action, leading to valued outcomes. His three stages are listed in Table 4.6.



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Table 4.5

Nelson-Jones Model of Helping

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Stage 1: Develop the relationship, identify and clarify problems. The task here is to 'build rapport and to help clients to reveal, identify and describe problems'.

Stage 2: Assess problems and redefine in skills terms. In this stage the task is to 'elicit relevant information to define problems in skills terms'.

Stage 3: State working goals and plan interventions. Working goals should now be stated and self-helping interventions negotiated to attain them.

Stage 4: Intervene to develop self-helping skills. The task is now 'to develop self-helping skills strengths in problem areas'.

Stage 5: End and consolidate self-helping skills. The helping contact is terminated and self-helping skills are consolidated.

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Table 4.6

Steps of Egan's Model of Helping

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- 1) identifying and clarifying problem situations.
  - 2) goal setting; developing and choosing preferred scenarios.
  - 3) action; moving towards the preferred scenario.
-

Stage 1: The principle here is to 'help clients identify, explore and clarify their problem situations and unused opportunities'. Clients are patients because they are stuck in a particular situation from which they cannot extricate themselves and which they feel is painful and problematic. The helper or nurse relationship helps the patient explore his or her current situation to identify specific problems of living that were not identified prior to the exploratory process. Egan feels this stage of his model is useful for exploring 'blind spots', or aspects of the client's life that had not been considered.

Stage 2: In this stage the client is helped to imagine a possible future situation that would be preferable to the present one. Egan states that clients are helped to 'identify what they want in terms of goals and objectives that are based on an understanding of problem situations and opportunities' once a realistic scenario has been discussed, the patient and the nurse can identify goals that can help in the achievement of the proposed future state (Egan, 1990a).

Stage 3: Ways are devised in which the preferred future ideal situation can be achieved. Clients are helped to 'develop strategies for accomplishing goals, for getting what they want'. All possible methods of achieving the desired outcome are identified and then a particular approach is selected. An action plan is drawn up in order to further aid the achievement of the plan. Finally the client puts the plan into action, supported by the helper (Egan, 1990c). Egan's three stage 'skilled helper' model serves as a useful and practical map in counselling and as a means of bringing structure to the helping process.

#### **4.7 Components of counselling skills**

Having outlined the psychological theoretical frameworks and models for implementation of a helping relationship it is now appropriate to address the attitudes and specific skills that are required for a nurse to translate theories into nursing practice. The counselling skills and help given by nurse are unique in that they take place in the context of physical or mental illness and pain, but this is only the most obvious and practical part of helping. What cannot be seen or touched is the patients' psychological suffering. With more and more emphasis being placed on holistic care and primary nursing, it is clear that both of these aspects of care need to be taken into account.

As the discipline of the use of counselling skills within nursing has grown, so it has become clear that those who use these skills need to have certain attributes and show certain skills. Tschudin (1995a) summarised these as genuineness, warmth and empathy, though not necessarily in that order. The order matters less because these skills will overlap and interact during the course of the counselling relationship.

There are a range of attitudes that a nurse needs to bring into any counselling relationship. These attitudes are such a basic requirement of any helping relationship that there is a great danger of us taking them for granted. They are summarised below:

**Attentiveness:** means being present in both body and spirit. The quality of the presence is what matters most. It is a willingness to be there for the other person, to accept anything that he or she may bring, a willingness to share yourself, your

time, your skills and gifts. Carkhuff (1987a) called attentiveness as a 'pre-helping skill' for the phases of helping, a skill that enables the client to become involved.

Non-judgmental attitude: being non-judgmental in a helping relationship does not mean 'anything goes', or that no judgements can be made at all. Indeed, we all have to constantly make judgements all the time to live. A non-judgmental attitude demands that a helper makes a suspension of premature solutions, of personal attitudes and of personal values. These last two items constitute attitude as described here, whereas the first refers more clearly to the skill of judging. Included with a non-judgmental attitude is a notion of respect, meaning that the person being helped is accepted for what he or she is. Nurses may find suspending their judgement to be a source of conflict in many cases, this is particularly so when strong views abound, for example in relation to issues of personal, religious, professional or political interest.

Being hopeful, the basic attitude of hopefulness from nurses is essential in a caring relationship, as many helping situations are created because of helplessness and hopelessness in clients. If a nurse is hopeful by attitude, then they are probably also supportive. The attitude of supportiveness means that it is necessary to form a relationship with someone to overcome a problem. The listed helper attitudes are not exclusive, but they need to be present in some form or other in any individual wishing to undertake effective helping.

#### **4.8 Core conditions of counselling**

Rogers postulated that there are three 'necessary and sufficient' core conditions for therapeutic change in counselling, namely, genuineness, warmth and empathy (Rogers, 1967).

The emphasis within 'core conditions' is placed on counselling skills as opposed to attitudes;

### *Genuineness*

Genuineness means, basically, that what is thought or stated is what is practised.

Egan who sees genuineness as 'beyond professionalism and phoniness', details very simply that genuineness has four aspects:

Not overemphasise the helping role.

Spontaneity.

Avoidance of defensiveness.

Openness.

This indicates that the more human and unaffected you are with patients, the more the helping will be real and effective (Egan, 1990d). Mearns and Thorne (1988a) summarised the skill of genuineness within counselling as a response to the client's expression; this response is either something persistent or striking with the client.

### *Warmth*

This component of a helping relationship has been described in many ways 'unconditional positive regard' is probably the best known. According to Mearns and Thorne (1988b) an unconditional positive regard is "the label given to the fundamental attitude of the person-centred counsellor towards the client. The

counsellor who holds this attitude deeply values the humanity of the client and is not deflected in that valuing by any particular client behaviours. The attitude manifests itself in the counsellor's consistent acceptance of and enduring warmth towards the client".

These authors call warmth an attitude, which indeed it is, but the skills they describe show that it is more than just an attitude. When patients are ill, they may appear vulnerable and that can lead very quickly to feelings of being useless, sad and fearful. In such a position it is not easy to be positive or sure about what decisions to make. This is one of the main reason why patients require more than reassurance in the form of unconditional positive regard.

There are many degrees of warmth that a nurse may show, ranging from a simple touch and a hug, between a smile and a phrase repeated frequently to underline that the nurse understands. It is not the nurse's warmth which patients need to see, rather they need to experience warmth that is adequate to their own personal needs.

### *Empathy*

Carl Rogers (1980) was the first to use the term as part of a counselling relationship. In 1980 he wrote what has become a definitive statement about empathy:

"It means entering the private perceptual world of the other and becoming thoroughly at home in it. It involves being sensitive, moment by moment, to the changing felt meanings which flow in this person, to the fear or rage or

tenderness or confusion that he or she is experiencing. It means temporarily living in the other's life, moving about it delicately without making judgements". A shorter and more cogent definition of empathy has been written by Kalish (1971) 'Empathy is the ability to perceive accurately the feelings of another person and to communicate this understanding to him (or her)'. One of the difficulties with the concept of empathy is clearly that Kalish views empathy in terms of skills whereas Rogers sees it as a 'way of being'. Skills are measurable and teachable, whereas the 'way of being' is far harder to quantify. Empathy is a very basic element in helping, but it cannot be separated from the other 'core conditions' of genuineness and warmth; this highlights the holistic nature of helping. It is perhaps worthwhile to stress that these 'core conditions' do not merely represent 'techniques' of counselling or psychotherapy, but are interpersonal skills that the counsellor employs in applying his techniques or expert knowledge.

#### **4.8.1 A critique of the core conditions of counselling**

Rogers claimed that if one or more of these conditions is not present, constructive personality change will not occur (Truax and Carkhuff, 1967). However, Truax and Carkhuff claimed that these three core conditions of effective therapy to be neither necessary nor sufficient. This insufficiency was indicated by the addition of a fourth ingredient of 'self exploration' and a further fifth ingredient of 'persuasive potency' (Truax and Carkhuff, 1968). The evidence presented by Truax and Carkhuff (1967) demonstrated that in many studies, including the Hopkins data and Wisconsin Schizophrenic Project, that

therapeutic changes were observed even though one of the three conditions was low (Watson et al. 1988). They concluded that the three 'core conditions' may be facilitative but they are not necessary in effective helping relationships.

#### **4.9 Counselling skills**

Listening and attending are by far the most important part of the counselling process. If, as nurses we can train ourselves to give our full attention to really listen to the other person, we can do much for them. Attending is the act of fully focusing on the other person and involves consciously making ourselves aware of what the other person is saying and of what they trying to communicate to us. Egan (1990d) has described attending, within his helping model with the acronym SOLER , highlighted in Table 4.7.

These guidelines illustrate the most important features of attending; being non-judgmental, showing positive body language, giving the individual space, staying open for the client and most importantly listening.

Listening is the beginning, middle and end of helping. It involves the process of hearing the other person, which not only involves noting things that the clients says, but also underlines a whole range of other aspects of communication that may be present. Three aspects of listening are noted in the Table 4.8:



Table 4.7 Egan's Model of attending

Squarely	Face the client Squarely. This can be meant both physically (sitting opposite)and metaphorically (conveying the message 'I am with you')
Open:	Adopt an Open posture. Crossed arms and legs can be signs of closing off. Your posture should convey 'I am open to you'.
Lean:	It is possible to Lean towards the other. Leaning towards the other person can be seen as 'I am interested in you'.
Eye:	Maintain Eye contact. This is a comfortable contact, not a staring. It is a way of saying 'I am with you, I want to hear what you have to say'.
Relaxed:	Try to be Relaxed. Nervousness and fidgeting are easily transmitted. This can make a client unsure even more uncomfortable.

Table 4.8

Aspects of listening skills

<u>Linguistic aspects</u>	<u>Paralinguistic aspects</u>	<u>Non-verbal aspects</u>
- words	- timing	- facial expression
	- volume.	- gestures
- phrases	- tone	-touch
	- pitch	- body position
- figures of speech	- ' ums' and 'errs'	- proximity to helper
- idiosyncratic forms of speech	- fluency	- body movement
	- range	- eye contact

Linguistic speech refers to the actual words the helper uses, to the phrases they choose and to the metaphors they use to convey how they are feeling. Paralinguistics refers to all those aspects of speech that are not words themselves. Non-verbal aspects of communication refer mainly to body language, the way clients express themselves through the use of their body. All of these behavioural considerations can help the listening process. In order to be effective they need to be used consciously.

A skilled counsellor learns to listen on all three aspects of communication, such listening is active in that it listens for something. It listens for the person, for all that he or she expresses. It listens, in particular, for feelings either expressed or hidden and it listens for the meaning that all this may have for the person.

Finally, it listens for a goal to emerge and for ways in which the person can or could change. The attending and listening aspects of counselling are essential skills that can be applied in every health professional's job and are not solely limited to the helping relationship and can be applied in other interpersonal exchanges.

Effective listening cannot take place if the helper has not first consciously considered the way we sit and the way we listen, it is possible to identify a range of conditions which can block effective listening. Egan (1990b) offers a useful list of possibilities that can potentially make effective listening to another person a problem.

- 1) Attraction: where the helper either finds the client either quite attractive or quite unattractive. More attention is paid to the way the helper feels than to what the client is saying.
- 2) Physical condition: the helper is sick or tired. Without realising it the helper tunes out some of the things the client is saying.
- 3) Concerns: the helper is preoccupied with their own concerns e.g they keep thinking about their own domestic problems.
- 4) Overeagerness: the helper is so eager to respond that only part of what the client says is taken onboard.
- 5) Similarity of problems: the problem the helper is dealing with are similar to their own. As the client talks, the helpers mind drifts into the implications the problem has to them.
- 6) Difference; the client and his or her experience is very different from the helpers. This lack of communality is distracting.

There are many other conditions which can interfere within a helping relationship, however those listed above have been pertinent in the undertaken study. There are many other issues which pose potential problems within counselling research, the following outlines these potential problems and steps that can be taken to resolve them.

#### **4.10 Problems encountered in counselling**

There are a variety of problems which can be encountered when moving through the outlined processes of a helping relationship. These potential problems are increased when the counselling relationship is part of a research project, with the implications this has both ethically and with regards to confidentiality.

The success of any counselling or helping relationship usually involves change on behalf of the client, such change may meet with resistance. Within helping relationships it often seems that individuals want problem resolution without having to change themselves. Clearly, life problems cannot change without the person who experiences them changing as well. The nature of counselling relationships then is one that develops, regresses, modulates and is finally outgrown. Along this dimension there are many ethical and moral dilemmas which can arise and a great variety of difficulties and obstacles that can result.

The purpose of giving counselling is to help people, or to empower them to help themselves, such a process can often require disclosure of confidential information, experience of painful memories and emotions and the taking of decisions that affect other people. Helpers should take great care to ensure that this process does not bring harm those receiving help. The practice of any counselling skills must include strong moral and ethical dimensions; it is advocated that the following ethical principles apply in helping relationships: that the helper considers the principles of the value of life, goodness or rightness, justice or fairness, truth-telling or honesty, and individual freedom when involved in any caring relationship. As previously stated research into counselling

introduces additional possibilities of harm. In this study the fact that randomly selected patients from an out-patient clinic were asked to attend counselling sessions highlights one of these dangers. Patients may be unwilling to participate in a clinical study regarding psychological well-being but may nevertheless comply for fear of antagonising the nurse within the institution whom he or she feels dependent upon to medically manage their chronic illness.

For the purpose of this study ethical approval was received from the Lothian Ethics Committee, giving an outline of the methodology of the study, one specific feature of this approval was to highlight within the consent form that if any patients randomised to the study declined to participate or chose to withdraw once they have been recruited from the clinical trial it would not in any way effect their medical management.

Confidentiality; Bond (1993) made a strong point for confidentiality within a helping relationship;

“A counsellor’s practice of confidentiality is closely associated with considerations of client autonomy. Confidentiality acts like a fence round the space created for the client’s autonomous actions. The fence is important to the client’s safety and creates the circumstances in which clients can look at issues which otherwise would be kept to themselves. The fence also marks a boundary of responsibility. Care over confidentiality reinforces the client’s sense of responsibility for the outcome of the counselling. Therefore confidentiality is extremely important in counselling. Care over confidentiality is a practical way of signalling respect for a client’s autonomy”.

Unless patients and clients know that they can trust their helpers, they are unlikely to talk openly about themselves to them. This is particularly true in the context of this study whereby the helper is not only providing counselling support but also acting in the capacity as a nurse specialist dealing specifically with nursing issues. In the present study, for instance, there were however situations when it was deemed necessary to break this confidentiality. In one instance a young female patient was showing signs of mental illness on assessment, after discussing the situation with the patient in question it was thought appropriate to refer her to the psychiatric services within the hospital. Making such a decision carried with it several difficulties; firstly persuading the patient that the nurse was not the best person to help with her problems and secondly referral to a psychiatric agency may be seen as a rebuff or as an indication that the patient is viewed as seriously mentally ill. In the case of this patient, the nurse felt it was in the patient's best interest to be reviewed by a psychiatrist and also felt unable to deal effectively with the situation specifically from the point of his own professional accountability. This was in line with the United Kingdom Central Council for Nursing and Midwifery (UKCC) Code of Professional Conduct (United Kingdom Central Council, 1992) which states that 'as a registered nurse, midwife or health visitor, you are personally accountable for your practice and in the exercise of your professional accountability must act always in such a manner as to promote and safeguard the interests and well-being of patients and clients'.

It is important that nurses working as counsellors only take on relationships that they can handle and in which they can be therapeutic. There are many such counselling type situations that nurses may not be able to help with adequately summarised in Table 4.9.

Table 4.9

Problematic counselling situations for nurses

- 
- 1) the person who is clinically depressed and talking of suicide.
  - 2) the person who is hallucinating or deluded.
  - 3) the person who has an organic mental illness.
  - 4) the person whose behaviour is potentially dangerous to themselves and others.
- 

The vast majority of helping relationships within the study were concerned with the ‘worried well’; people who had particular life problems but who were essentially mentally well. There is however a grey area between where ‘wellness’ ends and mental illness begins and in the rare event that a patient presented with any unmanageable psychological problem they were referred to the clinical psychologist/psychiatrist immediately.

It was decided that all patients should be told on recruitment to the study that the helping relationship will not be a confidential one and that certain people, for instance the consultant physician in charge of the patients medical care, may need to know about the content of the counselling conversations. This draws up a contract between the helper and the patient which is clear. Also the patient can

be reassured that people will only be given information on a 'need to know' basis. The importance of confidentiality and accountability cannot be stressed enough for any nurse involved in a helping relationship.

Transference and counter-transference must also be addressed as they can arise in any helping relationship, which involves the use of counselling skills.' Transference is the displacing of an emotion or attitude from one relationship to another' (Bayne et al. 1994). Generally it means that feelings and emotions belonging properly to previous relationships are transferred on to a current relationship. Peck (1993) views such feelings as inappropriate, intense, ambivalent and inconsistent and calls it 'the outdated map'.

Transference refers to the client coming to view the helper as if they were the all-forgiving, positive parent. As a result of increasing intensity of interaction, clients experience specific feelings towards helpers, these feelings range widely from admiring and affectionate to angry and rejecting .

Counter-transference, on the other hand refers to the unacknowledged feelings that the helper projects back to the client. If a helper acts in the role that is cast by the client, then they counter-transfer. In this instance the helper unconsciously colludes with the role the client has cast and the relationship staggers on until either the client finds little reward in it, as he will discover that the helper is 'only human' and the relationship will collapse.



#### **4.10.1 Burnout in counselling**

Burnout is another pertinent factor to be considered when using counselling skills in a helping relationship. The phenomenon of burnout occurs when workers enter a human service profession, such as nursing, with high and unrealistic aspirations regarding the degree to which they will be able to help other people. In many instances, the amount of help that can be offered, or the effectiveness of an intervention is limited. There are also, usually, too many clients to be dealt with in an ideal manner. The result is that the helper becomes caught between his or her own high standards and after a while is unable to maintain the effort and energy required to function at such a level. Stress and emotional and physical ill-health can result. The primary source of stress in relation to counselling help is the lack of therapeutic success. Farber and Heifitz (1982) listed overwork, working with clients raising personal issues and isolation as related to a state of burnout. Acting as both the researcher and the helper within this study it was very important to be aware of the causes of professional burnout when involved in helping relationships in order to avoid burnout; there follows a non-exhaustive list of potential causative factors in Table 4.10 .

On reflection there can be seen to be a high potential source of burnout when dealing with such an unpredictable and socially debilitating condition as IBD. Firstly the patients recruited for counselling did not seek additional help but were randomly selected to the study. Secondly there was a great deal of repetition in the form that the counselling support took and for long periods of

time it was not apparent whether the interventions were beneficial, all these factors do take a personal toll, however many preventive measures were taken to avoid the development of any form of burnout these are summarised in Table 4.11.

---

Table 4.10

Causative Factors of Burnout

---

- 1) Doing the same type of helping over and over again with little variation.
  - 2) Giving a great deal of one's own emotional and personal energy to other while getting very little back.
  - 3) Being under constant pressure to produce results in a certain time-scale when the time-scale and the pressure are unrealistic.
  - 4) Working with a difficult group; for example, those who are highly resistant to change, those who have been 'sent' for help but do not wish to be helped, or those for whom the chances of change are small because of the nature of their difficulties.(i.e terminally ill).
  - 5) The absence of support from immediate colleagues and an abundance of criticism.
  - 6) Lack of trust between those who engage in helping and those who manage the organisational resources that make helping possible.
  - 7) Not having the opportunity to take new directions, to develop one's own approach or to experiment with new models of working -being unnecessarily constrained ;
  - 8) Having few opportunities for training, continuing education, supervision or support;
  - 9) Unresolved personal conflicts beyond the helping and counselling work which interfere with the helper's ability to be effective; for example, marital problems, health problems.
-

Table 4.11

Measures to avoid development of burnout

- 
- vary work as much as possible
  - consider educational and training needs for future
  - take care of physical health
  - consider new ways of developing existing counselling skills
  - develop an effective supervisory and peer support network
  - nurture friendships and relationships with others
  - develop a range of interests outwith the workplace
  - attend 'refresher' workshops-as a means of updating skills
  - initiate projects, without relying on others to approve them.
  - seek positive and reliable feedback on your performance.
- 

Institutional constraints may also provide a source of burnout, within the nursing profession the use of counselling skills may result in conflict with colleagues and senior personnel as counselling is a time consuming, social influence process and many institutions view the use of such skills as outwith their job description. Jameton (1982) talks of such moral problems in nursing and reserves the strongest type, moral distress, for situations 'when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action'. It must be pointed out that no such institution conflicts existed within the study in question, but it is relevant to point out that institutional

constraints do exist within the nursing profession in the general medical setting not within the role of specialist nurse counsellor.

**PART TWO**

**CHAPTER FIVE**

**PILOT STUDY**

## **5.1 Introduction**

As discussed previously in Chapter two, HRQOL is affected by many factors including the severity of the disease, socio-economic factors, age, psychological aspects and personality. HRQOL measurement in IBD is also influenced by the efficacy and complications of treatment. Therefore, to obtain a true picture of the impact of the disease upon lifestyle and to fully define the specific areas of morbidity within the patient groups, a multi-dimensional approach was used to measure HRQOL in IBD patients.

## **5.2 Aim**

It was the aim of the pilot study to address the factors which most influence HRQOL in IBD and to define and quantify the patients' subjective view of morbidity associated with their disease. This was to identify the most important aspects which influence HRQOL for assessment in subsequent studies.

## **5.3 Subjects**

Over a twelve month period HRQOL analysis was performed on 140 IBD patients (70 with Crohn's disease and 70 with ulcerative colitis). The majority of subjects were resident in Edinburgh and as the population is relatively stable they provided an ideal cohort of patients for a cross-sectional study.

The Crohn's disease group ranged in age from 23-82 (median 43) years and 38 were female, 23% had ileal disease (n=16) and 77% had colonic involvement (n

54). Forty three percent of Crohn's patients had a history of bowel surgery, 32% had intestinal resection (n=22) and 11% had an ileostomy (n=8).

The ulcerative colitis group age range was 19-78 (median 45) years with 37 females. Eighty five percent of ulcerative colitis patients had extensive colonic involvement (n=60) and 14% had proctitis (n=10). None had undergone bowel surgery.

Diagnosis in all IBD patients was established by sigmoidoscopy, colonoscopy, rectal biopsy or air contrast barium enema. Median duration from time of diagnosis to assessment in IBD patients was 5 years (range 6 months-24 years).

Patients were taking a range of medications as shown in Table 5.1.

Table 5.1

Percentage patients medication in pilot study

Medication	Crohn's disease (n = 70)	Ulcerative colitis (n = 70)
Oral steroids	37	14
Azathioprine	20	13
Sulphasalazine	26	49
Mesalazine	34	37

Large joint arthropathy was the most commonly reported extra-intestinal manifestation, recorded at the time of randomisation in 18% (n= 13) of Crohn's disease patients and 16% (n=11) of ulcerative colitics. Other extra-intestinal manifestations recorded in <5% of the total patient group were skin lesions, ocular irritations and mouth ulcers. IBD patients with any other serious



concomitant disease and those unable to complete questionnaires were excluded from the study.

#### **5.4 Methods**

One hundred and forty consecutive IBD patients were selected for assessment from the gastrointestinal out-patient follow-up clinic. Patients were identified through screening of medical records prior to clinical attendance. Disease status, demographic details, past medical history and surgical history were recorded from their casenotes. On recruitment patients were provided with an information sheet and the study was also fully explained to the patient before written consent was obtained using a standard form (Appendix 5).

A multi-dimensional approach to measurement of HRQOL encompasses the assessment of physical, psychological, social and occupational dimensions of lifestyle. Physical disease activity was measured using the CDAI. Patients were supplied with a diary card, which recorded the number of soft or liquid stools, degree of abdominal pain and feeling of general well-being over a seven day period. This diary card was scored in conjunction with the physician's global assessment and the haematocrit to give an overall measurement of disease activity, classified as either mild, moderate or severe. Patients with ileostomy (n=8) were excluded from CDAI assessment.

The social and occupational dimensions of lifestyle were addressed with a disease specific formulated questionnaire addressing the impact of IBD upon lifestyle (Table 5.2). Additional social and occupational information was

recorded by the research nurse using a checklist as part of a structured interview (Table 5.3).

Psychological assessment was undertaken using the Hospital Anxiety and Depression Score Questionnaire (HAD). The questionnaire, which was self-administered by patients at their clinical visit, relates to individuals' emotional feelings during the past week. HAD consists of 14 items on two subscales (7= Anxiety; 7= Depression). Ratings by subjects are made on 4-point scales, which represent the degree of emotional distress; none =0, a little =1, a lot =2 and unbearable =3. Items were summed on each of the subscales and a score of 8 and above on either scale indicated the presence of a significant psychological problem.

These separate dimensions were scored independently as summing disparate dimensions of quality of life is not recommended because contradictory trends for different aspects of quality of life can be missed.

Table 5.2

Disease specific Questionnaire

Q1.	When did you first develop symptoms of IBD ?	Year _____
Q2.	When was a diagnosis made ?	Year _____
Q3.	Do you feel you received sufficient information about your disease ?	Yes / No
Q4.	What are you usual symptoms ?	
Q5.	Which is your worst symptom ?	
Q6.	Do you have full control over your bowel function ?	Yes / No
Q7.	Do you ever have to rush to the toilet ?	Yes / No
Q8.	Do you ever have "accidents" ?	Yes / No
Q9.	Does your bowel function affect;	
i)	Your family life ?	Yes No
ii)	Recreational activities ?	Yes No
iii)	Work life ?	Yes No
Q10.	Has your disease affected your relationships at home ?	Yes No
Q11.	Have you restricted your lifestyle because of your disease ?	Yes No
Q12.	Do you feel your disease has affected your quality of life ?	Yes No
Q13.	Do you feel your disease has affected your working life ?	Yes No
Q14.	How much time have you lost off work because of your disease	
Q15.	Have you had to change/lost your job because of your disease ?	Yes No

Table 5.3

Checklist for structured interview

CHECKLIST FOR PATIENTS	
PATIENT NUMBER	
NAME	TITLE; MR / MRS / MISS / MS.
ADDRESS	
CITY	
DATE OF BIRTH	AGE
MARITAL STATUS;	
DATE OF DIAGNOSIS	
FAMILY HISTORY OF IBD; YES / NO	DETAILS;
SMOKER; YES / NO / EX-SMOKER	IF EX-SMOKER, WHEN STOPPED
CURRENT TREATMENT;	
MEMBER OF NACC;	

## 5.5 Results

In both the Crohn's disease and ulcerative colitis groups diarrhoea was the most commonly reported physical symptom, occurring in 69% of Crohn's disease and 60% of ulcerative colitis patients. However it was with regard to control of their bowel function that patients reported the most social disability, 74% of Crohn's disease patients and 66% of ulcerative colitis reporting episodes of faecal incontinence (Table 5.4).

Tables 5.5 and 5.6 illustrates the impact of bowel dysfunction upon lifestyle, with regard to relationships at home; 57% of Crohn's disease patients and 51% of ulcerative colitis patients associated their disease with marital problems and difficulty in coping with children. Sexual dysfunction was reported in less than 5% of patients, this occurred in the younger female patients and usually related to the fear of faecal incontinence during sexual intercourse. Travel and holidaying problems, difficulty in participation in sport and attendance at any form of social function were cited as restrictions IBD placed on the recreational activities occurring in 66% of Crohn's disease and 54% of ulcerative colitis sufferers.

Disruption of occupational lifestyle related to disease was reported by 46% of Crohn's disease and 17% of ulcerative colitis patients. Reason cited for this disruption included difficulty gaining employment, difficulty gaining promotion whilst in employment, unsympathetic employers and poor relationships at work related to the social stigma of bowel disease.

With respect to the single question “Do you feel your overall quality of life is affected by your disease?”, 72% of Crohn’s disease patients and 68% of ulcerative colitics felt their IBD compromised their lifestyle.

Table 5.4

Physical symptoms reported by patients

Symptom reported	Crohn’s disease (n=70)	Ulcerative colitis (n=70)
Diarrhoea	48	42
Faecal Urgency	50	45
Faecal incontinence	70*	38
Rectal bleeding	5	23*
Weight loss	10	6
Abdominal pain	34	22
Tiredness	31	24

\* =  $p < 0.05$  (Chi-square test)

Table 5.5

Impact on social and occupational dimensions of lifestyle

Impact on social and occupational lifestyle	Crohn’s disease (n=70)	Ulcerative colitis (n=70)
Recreational activities	52*	46
Relationships at home	50*	45
Occupation	49*	38

\* =  $p < 0.05$  (Chi-square test)

Table 5.6

Patients control of bowel function

Question and response.	Crohn's disease (%)	Ulcerative colitis (%)
Do you feel that you have full control over your bowels ? No	52	46
Do you have to rush to the toilet ? Yes	50	45
Do you ever have "accidents"? Yes	49*	38
Does your disease affect;		
i) Family life. Yes	40	36
ii) Recreational activities. Yes	46	38
iii) Work. Yes	32*	12
iv) Make you anxious. Yes	28*	14

\* =  $p < 0.05$  (Chi-square test)

The HAD questionnaire demonstrated that anxiety, but not depression was common (Tables 5.7). The actual spread of anxiety scores is displayed in Figure 5.1, patients recording scores greater than eight are deemed to have case level anxiety. There were several sources of anxiety, 78% of Crohn's disease and 72% ulcerative colitis subjects felt that they had received insufficient information about their disease and this represented the major source of anxiety for them. Insufficient information with regard to drug therapy and potential side effects, dietary implications of IBD and the nature of the disease process itself were cited as areas required to be addressed. The majority of these patients felt that

additional information in these areas would enable them to adapt more satisfactorily to their disease. Reported sources of anxiety from patients are summarised in Table 5.9.

Table 5.7 Mean Hospital Anxiety and Depression Scores

n = 70	Crohn's disease	Ulcerative colitis
Anxiety	8.40 (3.5)	7.04 (4.6)
Depression	4.25 (4.4)	4.42 (3.5)

Standard deviations shown in brackets

Figure 5.1 Mean Anxiety Scores (HAD) for IBD patients at baseline.

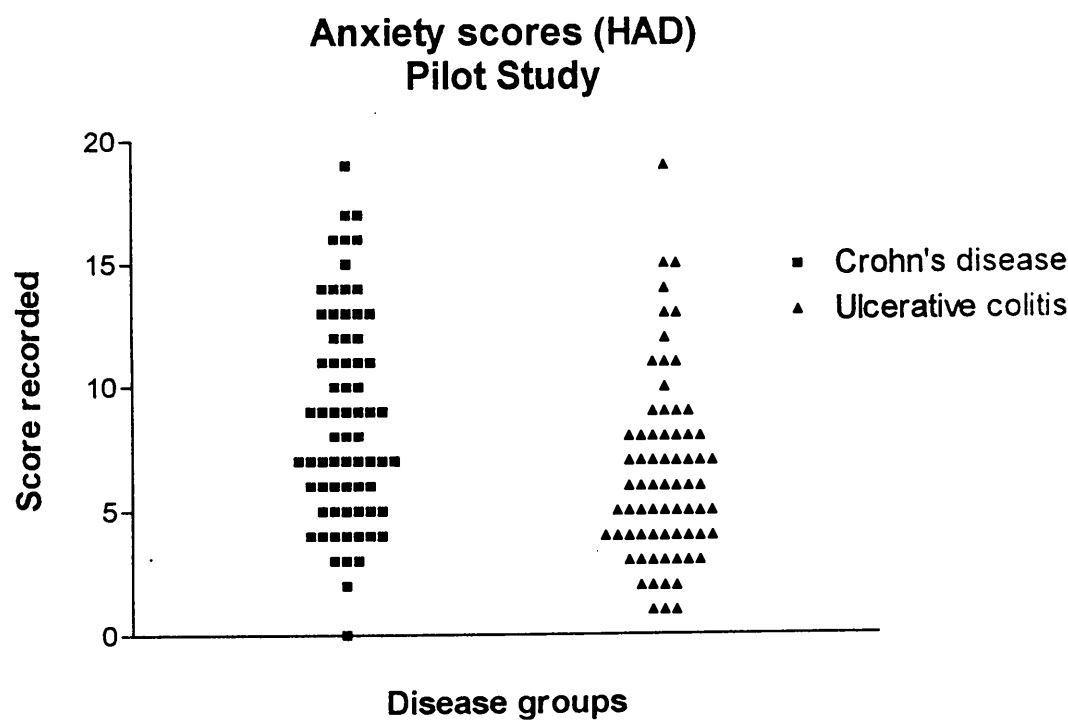




Table 5.8

Information Provision

Patient asked;	Crohn's disease	Ulcerative colitis
Do you feel you have received sufficient information regarding your IBD ? No	55	50
What would be the most beneficial form of information;		
i) Discussion with a doctor;	52	49
ii) Discussion with a specialist nurse;	50	45
iii) An information package;	50	50

**5.6 Summary and Conclusion**

Morbidity within all those dimensions examined, which included 18 specific problem areas was found, in all but one case (symptom of rectal bleeding), to be greater in patients with Crohn's disease than in those with ulcerative colitis. A Chi-square test was applied to the data in order to compare the difference between patient groups. A significant difference ( $p < 0.05$ ) was observed in several variables, related to bowel control, social and occupational aspects of lifestyle (See Tables 5.4, 5.5, 5.6). It was concluded that morbidity was greatly underestimated in this patient group, in particular with regard to Crohn's disease, causing high levels of social and psychological disability with disruption to lifestyle both at home and work. HAD scores indicated high levels of anxiety in

over a third of the Crohn's disease patient group, many of these patients reporting lack of information as a prominent stressor. Definition of high levels of morbidity in the physical, psychological and social dimensions highlighted the potential role for the use of appropriate counselling skills as part of the treatment regime in this patient group.

Table 5.9

Reported sources of anxiety in IBD

Commonly reported sources of anxiety	n	(%)
(n=140)		
Bowel urgency	99	(71)
Fear of incontinence "accidents"	87	(62)
Fear of cancer	23	(16)
Lack of information	104	(74)
Fear of surgery "ileostomy"	32	(23)
Social stigma of bowel disease	9	(6)

Information derived from the pilot study was used to construct the major study, in which the impact of a nurse led counselling service upon psychological morbidity in IBD was examined.

# **CHAPTER SIX**

## **METHODS**

## 6.1 Design

The pilot study, described in the previous chapter, demonstrated increased levels of anxiety in Crohn's disease patients. This may have occurred as a consequence of the physical symptoms of the illness, such as diarrhoea and faecal incontinence, the social or occupational consequences, lack of information, or the unpredictable future course of the disease. Having identified these factors, a prospective, randomised, longitudinal study was performed ;

- i) The aims of this were to compare quantify physical and psychological factors in patients with Crohn's disease and ulcerative colitis attending a gastrointestinal out-patient clinic. A healthy control group, recruited from a factory work force, and a disease control group, comprising patients with psoriatic arthritis, were assessed in an identical manner.
- ii) To examine the impact of psychological counselling in patients with Crohn's disease and ulcerative colitis.

The approach adopted in the provision of counselling support was based upon Egan's eclectic three stage 'skilled helper' model, which emphasises the mobilisation of the patient's own coping abilities. Physical and psychological morbidity were then reassessed at six months and 12 months. Morbidity scores were compared on entry and at each follow-up point.

## **6.2 Subjects**

### **6.2.1 Crohn's disease**

Fifty patients were identified by screening of medical casenotes prior to attendance at a gastrointestinal out-patient clinic (Appendix 1).

Inclusion criteria :

- 1) Established diagnosis based upon clinical history and laboratory, radiological and endoscopic tests.
- 2) Regular and reliable attendance at the gastrointestinal out-patient clinic.
- 3) Aged between 16-65 years.
- 4) Ability to understand and complete the questionnaires.

Exclusion criteria :

- 1) Aged less than 16 or greater than 65 years.
- 2) Serious co-morbid disease, severe enough to interfere with lifestyle.
- 3) Pregnant.
- 4) Unable to understand or comply with the study or questionnaire.

Twelve patients (24%) within the Crohn's disease group had isolated ileal disease, 10 patients (20%) had Crohn's colitis and 28 (56%) had ileo-colonic involvement. The age range of this group was 16-64 years (mean 43 years) and 34 were females. The diagnosis was based upon a typical clinical presentation of abdominal pain, diarrhoea, weight loss, tiredness, perianal disease and extraintestinal manifestations. Large joint arthropathy was the most commonly reported extraintestinal symptom reported by 10 patients (20%), seven patients (14%) reported dermatological complications and less than five percent reported

ocular problems. Diagnosis was based on sigmoidoscopy with rectal biopsies, colonoscopy with multiple biopsies, air contrast barium studies and barium follow-through.

At the time of randomisation patients were taking a number of medications, as shown in Table 6.1.

Table 6.1

Medication in Crohn's disease

DRUG	No. of patients	%
Salazopyrin	14	28
Mesalazine	31	62
Prednisolone	17	34
Azathioprine	16	32

Several patients had previously undergone abdominal surgery, a summary of which is presented in Table 6.2. Patients in some instances had required more than one resection, seven patients had required two operations and one had undergone four resections.

Table 6.2

Surgical Management in Crohn's disease

SURGERY	No of patients	%
Ileal Resection	17	34
Colectomy and Ileostomy	6	12
Abscess drainage	2	4

**6.2.2 Ulcerative colitis**

Fifty patients were recruited from the same gastrointestinal out-patient clinic using an identical screening process (Appendix 2).

Inclusion criteria :

- 1) Established diagnosis based upon clinical history and laboratory, radiological and endoscopic tests.
- 2) Regular and reliable attendance at the gastrointestinal out-patient clinic.
- 3) Aged between 16-65 years.
- 4) Ability to understand and complete the questionnaires.

Exclusion criteria :

- 1) Aged less than 16 or greater than 65 years.
- 2) Serious co-morbid disease, severe enough to interfere with lifestyle.
- 3) Pregnant.
- 4) Unable to understand or comply with study or questionnaire.

Twenty seven patients were female and their age ranged from 17-60 (median 27) years. The diagnosis in this group was based upon a typical clinical

presentation of chronic diarrhoea with blood and mucous and was confirmed in each case by either endoscopic examination and/or barium enema. Forty three of the ulcerative colitis patients had extensive colonic involvement (86%) and seven had proctitis alone (14%).

Large joint arthropathy was the most commonly reported extraintestinal manifestation in the ulcerative colitis group occurring in a quarter of this patient group. Less than five percent of ulcerative colitics reported iritis, aphthous ulcers and one case of pyoderma gangrenosum was recorded.

Patients were taking a range of medications for their condition, which are summarised in Table 6.3. Many of the patient group were taking more than one medication.

Table 6.3

Medication in ulcerative colitis

Drug	No of patients	%
Sulphasalazine	18	36
Mesalazine	33	66
Prednisolone	12	24
Azothioprine	11	22

No patient within the ulcerative colitis patient group had undergone any form of bowel surgery prior to recruitment into the study.



6.2.3 Healthy volunteers

Fifty volunteers were recruited from a local factory workforce. Individuals completed a medical history checklist and had no gastrointestinal symptoms, serious psychological or physical illness or surgical operations. The age range of this group was 17-62 years (mean 40) and 27 were females.

6.2.4 Psoriatic arthritis

Twenty eight patients were identified through the screening of a rheumatology out-patient clinic (Appendix 3). The diagnosis of psoriatic arthritis was based upon a typical history of arthritis associated with psoriasis and confirmed by joint and skin examination, which was undertaken by a Senior Registrar in rheumatology. Table 6.4 highlights the severity of arthritis in this patient group based on the physician’s joint examination, and was based upon the number of inflamed or painful joints. The age range of this group was 19-64 years (mean 34) and 28 were female.

Table 6.4 Active arthritis in psoriatic arthritics

Severity of arthralgia.	Patient No.	%
None	1	4
Mild	22	44
Moderate	11	22
Severe	6	21

These patients required a wide number of medications, principally non-steroidal anti-inflammatory drugs to manage their disease (Table 6.5).

Table 6.5

Medication in psoriatic arthritis

Drug	No. of patients	%
Methotrexate	14	50
Sulphasalazine	7	25
IM Gold	2	7
Regular analgesia	14	50

**6.3 Protocol**

**6.3.1 Consent**

Prior to inclusion to the study all participants received a patient information sheet (Appendix 4) and were given an opportunity to ask questions regarding the study. All completed a standard written consent form (Appendix 5 ).

**6.3.2 Randomisation**

Patients were assigned a study number and were randomised, using a sealed envelope method, whereby envelopes containing randomisation codes were opened on recruitment to the study to determine whether the patient would receive either counselling support (active treatment) from the research nurse or routine clinical follow-up. Randomisation ensured that there was no bias in the treatment allocation and that patients in each treatment group were comparable in both known and unknown prognostic factors.

### 6.3.3 Ethical considerations

A controlled, randomised, prospective study of IBD patients has several ethical implications. These relate to patient confidentiality, anonymity and the withholding of what is generally perceived as optimal management (counselling) from some patients. The safety of psychological interventions (*'Challenge of Change'*) was considered prior to commencement of the study to protect patients from potential harm or distress.

It was deemed unethical to conceal important information and support from patients followed-up routinely and therefore all IBD patients received the written information booklet, *'Living with Inflammatory Bowel Disease'*, provided by NACC, a national IBD support group. Routinely followed patients were provided with a local contact address for NACC which provides both information and emotional support in the form of a confidential telephone counselling service. The research nurse was also available on request at the out-patient department to give relevant advice and basic help with any medical or social problems to all IBD patients. Ethical permission was given by the Lothian Medicine/Clinical Oncology Research Ethics Sub-Committee (1702/93/4/146).

#### **6.4 Initial assessment and follow-up**

IBD patients, psoriatic arthritic patients and the healthy volunteers were all assessed at baseline. IBD patients were further assessed at 6 months and 12 months.

##### *Physical Assessment*

Measurement of physical disease activity within IBD patients was based upon the CDAI. Previous studies have shown that this is applicable to both Crohn's disease and ulcerative colitis (Helzer et al. 1982). Clinical assessment was undertaken by medically qualified personnel who had no prior knowledge of whether the patients were to receive active counselling or routine support. Medical notes were examined by the research nurse to gain relevant demographic details and past medical history, including surgery. Structured interviews were performed at each clinical visit and a routine blood sample was obtained for haematological and biochemical tests.

All IBD patients were given a diary card (Appendix 6) which was completed on a daily basis for the seven days prior to each clinical visit. This addressed the severity of specific symptoms and state of well-being. In conjunction with clinical and laboratory assessment it was used to provide an overall measurement of physical disease activity. Patients were graded as having mild, moderate, or severe disease activity.

As there is no recognised disease index for patients with psoriatic arthritis, the physical disease activity assessment was based upon the physician's clinical

assessment using a modified joint score, haematological results, a visual analogue pain score and a measurement of the extent of psoriasis.

#### *Psychological assessment*

The psychological assessment of all participants was measured using three validated psychological measurement tools; the Hospital Anxiety and Depression Score (HAD) (Appendix 7); the Styles and Strategy questionnaire (SS) (Appendix 8) and the Attitudes and Preferences questionnaire (AP) (Appendix 9). These questionnaires were scored and interpreted independently. In addition at each assessment all participants completed a life events table (Appendix 6), of positive and negative events during the preceding month.

#### *Disease specific assessment*

Based upon the literature review and the findings of the pilot study undertaken a 15 item disease specific questionnaire was developed to measure HRQOL in IBD (Shown in Table 6.6). Exploratory factor analysis was applied to the data from the disease specific questionnaire to examine the relationship between different aspects of HRQOL, the principles of which are described in Chapter Seven. Statistical analysis was similar to that described by Watson and Deary (1994) in the development of a scale measuring feeding difficulties in patients with dementia.

Exploratory factor analysis, involving principal components analysis followed by oblique rotation was performed by a networked version of the statistical package for social sciences (SPSS) PC+ version 4.0.1. This statistical package was also

used to determine the internal reliability of the items used in the construction of the IBD disease specific questionnaire by means of Cronbach's alpha.

*Generic health status assessment*

The Short Form 36 (SF36) health survey questionnaire was completed at each visit.

Table 6.6

IBD Questionnaire administered to patients

---

- 
- Q1 Do you feel that sufficient information was given to about your disease ?
- Q2 Are you familiar with the National Association of Colitis & Crohn's disease ?
- Q3 Over past two weeks have you had diarrhoea ?
- Q4 Over past two weeks have you had tummy pain ?
- Q5 Over the past two weeks have you been overly tired ?
- Q6 Over the past two weeks have you had joint pain ?
- Q7 Do you feel you have full control over your bowel function ? (If No, go to Q13)
- Q8 Do you ever have to rush to the toilet, regarding your bowels ?
- Q9 Do you ever have accidents, regarding your bowels ?
- Q10 Does your bowel function affect your relationships at home ?
- Q11 Does your bowel function affect your social life ?
- Q12 Does your bowel function affect any recreational activities you normally do ?
- Q13 Do you feel your recreational activities are restricted by your disease ?
- Q14 Do you feel your disease has affected your relationships at home ?
- Q15 Do you feel your overall "Quality of Life" is affected by your disease ?
- 

Possible responses to Q1-2, Q7-12: Yes=1 No=2, Q3-6, Q13-16; 0 = Not at all.

1= A little, 2=Moderately 3=Severely.

## 6.5 Intervention

The counselling package had two main themes; i) information provision and ii) psychological intervention.

i) Information provision: patients randomised to active support were provided with a range of written material. In addition to the NACC '*Living with Inflammatory Bowel Disease*' leaflet, patients were provided with educational booklets on diet, drugs, tests, surgery, employment and travel. An educational video entitled '*What you really need to know about Crohn's disease/ulcerative colitis*' was also supplied. This video provided information for IBD patients and was suitable for close relatives, friends and employers. Patients and relatives had access to a multi-disciplinary team including a pharmacist and a dietician for advice about specific problems.

ii) Psychological intervention: this was based upon a programme of stress management devised by Roger at the University of York. This programme, the '*Challenge of Change*' was adapted to meet the specific needs of IBD patients. Intervention was based on the core of the '*Challenge of Change*' programme, modules related to managerial skills and work skills strategies within the programme were omitted because they were deemed not applicable to IBD subjects. This package was given to the active treatment group during a two hour consultation away from the clinical environment of the out-patient department. The core of the '*Challenge of Change*' includes the following themes;



### *The Source of Stress*

A short introductory talk was given to each patient about the sources of stress. The most important assumption underlying the stress management programme is that stress is not a property of an event, but results from perception, and reactions to an event. Individual differences are consequently pivotal in determining whether or not an event becomes a source of stress and this point is highlighted during the 15 minute presentation. Patients were told that stress associated with an emotionally upsetting event can be provoked by rumination. Emphasis was placed on the proposition that stress is a preoccupation with emotional upset. To meet the challenge of change which follows emotional distress the individual has to wake up from nightmares about the past and to minimise worries about the future by 'controlling attention'.

### *Personality*

The '*Challenge of Change*' programme involves assessment of personality traits, using the Attitudes and Preferences questionnaire. Personality scales include the four scales, locus of control, a measure of tolerance for change and a scale for assessing Type-A behaviour pattern. Patients scores were entered into a computer spreadsheet and the interpretation of the scores was discussed at length with the individual, with the emphasis on the opportunities for change in the behaviours described by the scales. These were then linked to the exercises described in the following sections.

### *Physical Relaxation*

The practical techniques of intervention begins by stopping, checking and releasing tension. The emphasis is on the development of a rapid release from tension with a 'stop-check-relax' routine which takes no more than a few seconds to perform. This exercise is augmented by a more systematic and prolonged programme of progressive relaxation over a thirty minute period in a quiet, darkened room and is supported by an audio cassette. After practice during the session the individual repeats the process on a regular basis in their own home. The physical relaxation programme is based on the principle of two "gates", cervical and pelvic, and the system involves progressive relaxation by releasing tension held which is impeded by the two gates (Roger and Nash, 1993a).

### *Attention Control*

The next stage of the programme is based on the theory that tension arises in the mind rather than in the body; the body simply reflects mental tension. The practice of attention control ("mental relaxation") commences with the patient using the same stopping and releasing procedures as with physical relaxation and this followed by focusing of attention onto the immediate surroundings. This brings the patients attention under control and away from rumination about emotionally upsetting events, past or future. The aim of this exercise is to disengage from the entanglements of emotionally distressing mental imagery. An audio cassette is used to reduce the duration of the period between a stressful event and its resolution.

### *Coping and Detachment*

On recruitment, patients are provided with a second questionnaire, the Styles and Strategies or the Coping Strategies questionnaire (CSQ), which is completed and scored prior to attendance. The CSQ identifies four different coping strategies: detached, rational, emotional and avoidance. Detached and rational coping are adaptive and involve active information processing and emotional disengagement, whilst emotional and avoidance are maladaptive. Distinction is made between the two very different coping styles which are explained to the patient in the programme by the analogy of a house with two doors, but with a flood pressing up against only one of the doors. The house is the mind and the flood is the unseen store of memories with their associated emotions, all pressing for attention. One way of trying to cope with this situation is to pile the furniture up against the door and hope it all goes away, in other words, to use denial. It is stressed to the patient that this means of coping is counter productive and at some point the pressure forces down the door and the individual will drown in the emotional flood. This process is graphically illustrated to the patient by unresolved post-traumatic shock, which may be triggered many years after a stressful event. A second analogy of a house with saloon doors that open at will is used to illustrate an emotional coping mechanism. This is the everyday experience of repeatedly returning mentally to the scene of stress, recasting our part within it and with our attention again drowned in the emotional flood. To address these two maladaptive strategies of stress management the patient must

first realise that the emotional flood will not go away of its own accord and pretend it does not exist. Secondly, it is illustrated to the patient that if the house has a loft, the analogy can be used that we first open the door opposite the flood, then open the other door and go into the loft while the emotional problem passes through below. This simple analogy is used to teach the patient how to address problems related to their disease by 'opening the doors and be in the loft'; encouraging them to acknowledge their existing problems but not to drown in them. In other words, not to let their disease govern their lifestyle. Physical relaxation and attention control techniques are central to this programme of emotion disengagement. The patient is reminded that the key to the '*Challenge of Change*' programme lies with themselves and their own self-knowledge, by remembering to stop, physically and mentally, and practising to be detached and rational when dealing with stressful situations.

### *Recognising Limitations*

This component of the session is related to locus of control, and emphasises to the patient the importance of relinquishing control in circumstances which are beyond control.

### *Social Support*

The patient is offered the opportunity of expressing emotions arising from conflict and distress that may result from their disease. This support can conveniently be divided into two main categories namely 'extended' and 'intensive'. Extended social support provides the patient an avenue to confide feelings and emotions about their illness that may previously have been inhibited.

This form of extended social support offers the opportunity for ventilating such feelings, thus reducing their potency for provoking rumination.

In many instances in the study intensive social support was provided by myself by providing professional help when the individual was no longer able to cope.

In specific cases where professional psychological intervention was deemed necessary psychotherapy was provided by referral to a clinical psychologist.

#### *Follow-up*

The number of follow-up sessions varied according to the requirements of the patients. The follow-up was intended as a review of the learned practises, strengthening them where required, and monitoring patients progress. Patients randomised to '*Challenge of Change*' were given the option of additional teaching and counselling sessions.

**CHAPTER SEVEN**  
**STATISTICAL METHODS**

## 7.1 Summary Statistics

Initially, the data is presented in the form of summary statistics, including measures of central tendency: the mean, median and mode, and distribution using the standard deviation. The mean ( $\bar{x}$ ) is the sum of all the observations divided by the number of observations and provides a useful summary statistic which may be incorporated in further analysis. The median is the centre of the distribution whenever the observations are placed in order or ranked such that half of the observations lie above and below it and is most useful whenever the distribution of the data is skewed, although it can be used with a normal distribution. The mode is the most common observation in a set of data and is of limited use. In normally distributed data, the mean, median and mode coincide forming the central point of distribution.

In addition to measures of central tendency, some measures of the spread of the data about the central point are required to describe the distribution. The most commonly used measure of distribution is the standard deviation. Standard deviation (SD) is a summary measure of the differences of each observation from the mean and it represents the average amount of deviation from the mean. The standard deviation is calculated by squaring the difference between each data point and the mean. The sum of the squares is then divided by the number of observations minus one ( $n-1$ ) to give the mean of the squares and the square root of this value is taken to give the standard deviation, hence:

$$SD = \sqrt{\frac{\sum (x - \bar{x})^2}{n-1}}$$

here, n = number cases, x = individual case,  $\bar{x}$  = sample mean

The division by the number of observations minus one instead of the number of observations to obtain the mean square is because the degree of freedom (n-1) leaves only n-1 ways in which the rest of the sample can be chosen. This reflects that ordinarily a sample has less diversity than is found in its parent population (Swinscow, 1996).

When the population from which the data arise have a distribution that is approximately 'normal' (or Gaussian), then the standard deviation provides a useful basis for interpreting the data in terms of probability, especially in the context of statistical inference. Normal distribution is represented by a family of curves defined uniquely by two parameters, the mean and the standard deviation of the population. The curves are always symmetrically bell shaped with most of the values clustered around a central value, with increasingly smaller frequencies located further from the centre. The standard deviation provides a useful measure of the scatter of observations in that, if the observations follow a normal distribution, the range covered by one standard deviation above the mean and one standard deviation below the mean ( $\pm 1$  SD) includes approximately 68% of the observations; a range of two standard deviations above and two below the mean ( $\pm 2$  SD) in 95% of the observations; and of three standard deviations and three below ( $\pm 3$  SD) in 99.7% of the observations. In a perfectly normal distribution one, two, or three standard deviations above and below the mean include 68%, 95% and 99.7% of the observations respectively (Donnan, 1991).



## **7.2 Parametric Testing**

Bryman and Cramer (1996) state that one of the unresolved issues in data analysis remains the question of when non-parametric rather than parametric tests should be used. Non-parametric tests are so named because they do not depend on assumptions about the precise form of the distribution of the sampled populations. Parametric tests make assumptions about the distribution of the data in the population from which the sample is drawn, namely that the level of measurement is of equal interval or ratio and the distribution of the population scores is normal, and also that the variance of both variables are equal. Parametric statistics are based on the assumption of a normally distributed population whose standard deviation is known and can thus be estimated from sample data. In this study parametric tests have been used thereby making the safe assumption, on the basis of Bryman and Cramer guidelines, that the variables examined fulfil parametric criteria (Bryman and Cramer, 1996).

## **7.3 The t-Test**

The t-test is commonly used for testing the statistical significance of the difference between two normally distributed means. The t-test may be used to determine the statistical significance of the difference between the means of two groups, within groups across time and the difference of a group mean from the population mean. The significance level of a t-test is usually set at a probability

(p value) of 0.05 indicating that there is only a five in one hundred probability that the difference between the means occurred by chance.

When hypothesis testing is carried out, two sorts of error can occur. Firstly the null hypothesis (that there is no difference between the means) may be rejected when in fact it is true and this is called a type I error. Alternatively, the null hypothesis may not be rejected when it is incorrect and this is known as a type II error. The probability of correctly assuming that there is a difference when there actually is one is known as the 'power of a test'. The power is simply 100 % minus the probability of a type II error and is thereby the probability of rejecting the null hypothesis given that it is false. A powerful test is one that is more likely to indicate a significant difference when such a difference exists (Polit and Hungler, 1995a).

The t-test compares the difference between the two means using the standard error of the difference in the means of the two samples. The standard error is the standard deviation of repeated estimates of the mean and estimates how close a sample mean is to the mean of the population from which the sample was drawn.

The value of t is calculated as follows:

$$t = \frac{\text{sample of mean 1} - \text{sample mean 2}}{\text{standard error of the difference in means.}}$$

However the precise formula differs for the different conditions (i.e within group and between group) outlined above. The calculated value of t should be larger than a tabulated value of t which is located by the significance level of the test and the degrees of freedom.

#### **7.4 Analysis of variance**

Analysis of variance (ANOVA) is analogous to the t-test in that it allows for comparison of two means simultaneously in order to determine whether or not there is a statistically significant difference between two or more means. The simplest form of ANOVA is one way analysis of variance in which the mean values of interval or ratio-level data are compared. ANOVA is based on a comparison of two sources of variance in the sample; between and within group. For the ANOVA test a value of  $F$  is calculated which should satisfy the conditions for the calculated value of  $t$ , for the t-test, as described above.

#### **7.5 Multivariate Analysis of Variance**

Multivariate analysis of variance (MANOVA), is an extension of ANOVA procedures to more than one independent variable. This statistical procedure is used primarily to test the significance of differences between the means of two or more dependent variables, considered simultaneously.

#### **7.6 Correlation**

Correlation estimates the strength of an association between two variables and indicates both the strength and the direction of a relationship between two variables. For interval or ratio level variables the appropriate test of correlation is Pearson's Product Moment Correlation Coefficient, referred to as Pearson's  $r$ .

The correlation coefficient is expressed from +1 to -1. Complete correlation between two variables is expressed by either +1 or -1. When one variable increases as the other increases the correlation is positive, when one decreases as the other increases it is negative. Complete absence of correlation is represented by 0. The closer  $r$  is to 1, whether positive or negative, the stronger the relationship between the two variables. The nearer  $r$  is to zero (hence the further it is from +1 or -1) the weaker the relationship.

Scatterplots or scatterdiagrams may be used to represent the relationship between variables, representing for each case the points at which the two variables intersect. In the interpretation of correlation it is important to remember that correlation does not, necessarily imply causation. There may or may not be a causative connection between two correlated variables but more sophisticated methods of analysis are required to determine this. The coefficient of determination ( $r^2$ ) provides an aid to the interpretation of Pearson's  $r$  and this is the square of  $r$  multiplied by 100 and it provides an indication of how far variation in one variable is accounted for by the other. Therefore, if  $r = -0.5$ , then  $r^2 = 25$  per cent. This means that 25 per cent of the variance in one variable is due to the other.

## **7.7 Factor Analysis**

As highlighted in Chapter Six the major purpose of factor analysis is to reduce a large set of variables into a smaller, more manageable set of measures. Factor analysis disentangles complex interrelationships among variables and identifies which variables go together as unified concepts (Hair et al. 1987). The first

phase of factor analysis is usually referred to as the factor extraction phase. The most widely used method of factor extraction is principal components analysis the purpose of which 'is to determine factors (i.e principal components) in order to explain as much of the total variance in the data as possible with as few of these factors as possible' (Dillon and Goldstein, 1984).

The first outcome of principal components analysis is a factor matrix, which contains coefficients or weights, analogous to Pearson's  $r$ , for each variable in the original data matrix on each extracted factor. Initially, principal components analysis extracts as many factors as there are variables, assigning each factor an Eigenvalue equivalent to the number of variables explained by the factor. The Eigenvalues may be used to decide how many factors to extract and, conventionally factors with Eigenvalues greater than one are considered to be worth extracting (Walsh, 1990). The maximum amount of variance is extracted by the first factor. The second factor extracts the highest possible amount of variance from what remains after the first factor has been taken into account and so on. Principal components analysis thereby indicates the number of factors to which the initial data can sensibly be reduced and indicates the amount of variance which is accounted for in each of the variables across the retained factors. However, in order to achieve a simple structure within the data, whereby the loading of variables on factors will make most sense by maximising the loadings of variables on putative factors. Child (1990) outlines that further analytic steps called rotations that are required. Rotations can be achieved either orthogonally or obliquely. In orthogonal rotation, factors are assumed to be

unrelated and are therefore uncorrelated with one another. Oblique rotations, on the other hand, assume a relationship between the factors. Rotation achieves the distribution of the common variance in the variables more evenly across the rotated factors. Simple structure is achieved when Thrustone's criteria of maximal loading of unique variables on factors is achieved (Child, 1990). It is conventional, in factor analysis, to have at least five subjects per variable (which in this case means 'question') and not less than 100 subjects per study (Bryman and Cramer, 1990).

#### *Cronbach's Alpha*

In scale development, of which factor analysis is an integral part, it is essential to establish the reliability of the factors and this may be achieved by estimating the internal consistency. This may be done conveniently by calculation of Cronbach's alpha which is the average of all split-half methods of estimating internal consistency. Cronbach's alpha is widely used and is also referred to as the coefficient alpha (Polit and Hungler, 1995b). The normal range of values for Cronbach's alpha is between 0 and 1, a Cronbach's alpha of 0.80 or above is conventionally used to indicate acceptable internal reliability (Bryman and Cramer, 1994).

# **CHAPTER EIGHT**

## **RESULTS**

## 8.1 Introduction

Results are presented in the following order. First, the mean scores from the assessment scales are presented for all study groups followed by differences in means between the study groups which were tested with one way analysis of variance and t-tests. Significant differences are indicated in the relevant tables.

The impact of a counselling service upon IBD patients was re-examined at six months and again at one year principally with the use of t-tests screening for any differences across time. Multivariate analysis of variance (MANOVA) was employed in instances of differences and results from these analyses are incorporated in the relevant tables. The inter-relationship of all variables was examined using a correlation matrix which provided a basis for the development of a disease specific questionnaire.

All statistical testing, with the exception of factor analysis, was performed using the statistical software package Minitab 8.0 (Minitab Inc. USA). Statistical Package for Social Sciences (SPSS PC+) was used for exploratory factor analysis. Statistical significance was accepted at  $p < 0.05$  in analysis of results.

For the purpose of analysing results IBD patient groups are broken down into those who received active counselling and those who received general support.



8.2 Presentation of results

*Crohn's disease activity index (CDAI)*

The modified CDAI assessment was used in Crohn's disease and ulcerative colitis patients. The mean scores are presented in Table 8.1, as the CDAI is not validated for use in ileostomy patients, these patients were excluded from CDAI measurement. Disease activity assessment in the psoriatic arthritic group was based upon clinical assessment, as no published psoriatic arthritis disease activity assessment tool exists. Details of psoriatic arthritic patients are given in Chapter Six (Table 6.4). Like the IBD patients the majority of psoriatic arthritis patients had only mildly active disease.

Table 8.1

Mean modified CDAI scores for IBD patients

		Baseline	Six months	Twelve months
n				
Crohn's disease *	23	138.7 (77.8)	127.6 (72.0)	113.8 (70.1)
Crohn's disease	21	138.3 (86.1)	128.6 (58.1)	114.9 (68.4)
Ulcerative colitis *	25	96.3 (50.1) <sup>‡</sup>	80.26 (42.0) <sup>‡</sup>	78.6 (43.1) <sup>‡</sup>
Ulcerative colitis	25	85.8 (50.7) <sup>‡</sup>	79.57 (42.1) <sup>‡</sup>	75.1 (41.2) <sup>‡</sup>

\* = active counselling.

Standard deviations are shown in brackets.

‡= p <0.05 for Crohn's disease vs. ulcerative colitis patients (t-test).

As shown in Table 8.1 CDAI scores were significantly higher in the Crohn's disease group compared to the ulcerative colitis patients. Although statistically significant, the clinical significance of this observation is relatively modest, as only differences in CDAI scores greater than 50 are said to be of clinical importance (Summers et al. 1979).

The majority of IBD patients had mild disease, only 8% of Crohn's disease patients and no ulcerative colitics had severe disease on recruitment, although this is not surprising in an out-patient population (Table 8.2). It was noted that, of the items constituting the CDAI, no single component predominated.

Table 8.2

Breakdown of degrees of severity in CDAI scores for IBD patients

	n	Mild (%) CDAI<150	Moderate (%) CDAI 150-250	Severe (%) CDAI >250
Crohn's disease	44	25 (58)	15 (34)	4 (8)
Ulcerative colitis	50	45 (90)	5 (10)	0 (0)

Percentage shown in brackets.

The mean CDAI score of both Crohn's disease and ulcerative colitis patients tended to improve during the one year period of the study. This applied equally to patients who received counselling or general support (Figure 8.1).

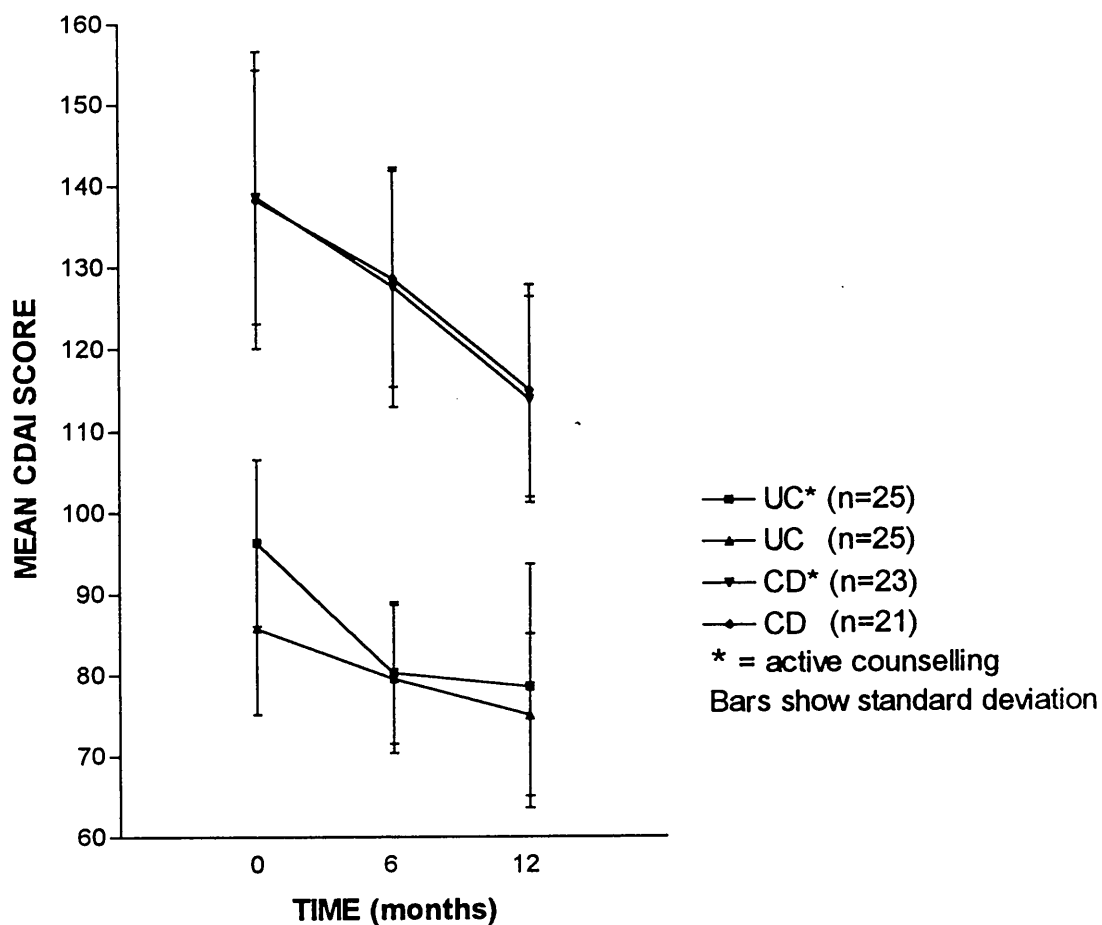


Figure 8.1 Mean modifiedCDAI scores for IBD patients

Crohn's disease patients with ileostomy have been excluded from CDAI measurement.

### *Short-form 36 (SF36)*

Patients with chronic physical illness consistently recorded lower mean scores for the eight dimensions of the SF36 than healthy volunteers, although these were statistically insignificant (Table 8.3). The healthy volunteer responses were comparable with the normative general population data generated by Jenkinson et al. (1993) for similar sex and age distribution.

Scores were similar in IBD patients receiving active counselling and general support and overall IBD patients, scores were consistently lower than those of the psoriatic arthritis control group. The greatest difference occurred in the domain of social function which was significantly lower in IBD patients. In contrast, psoriatic arthritic patients recorded a lower physical role function score. Reassessment scores recorded by both Crohn's disease and ulcerative colitis patients remained fairly consistent regardless of whether they received counselling or general support with the one exception of improvement in the domain of mental health for Crohn's disease patients receiving active counselling (Tables 8.4 and 8.5).

Table 8.3

Mean SF36 scores for control groups versus IBD patient groups at baseline

	Psoriatic	Healthy	Crohn's	Ulcerative
	arthritis	volunteers	disease	colitis
n	28	50	50	50
Physical function	74.3 ( 8.0)	89.4 (6.7)	70.6 ( 9.2)	75.6 (8.8)
Social function	80.2 (10.2)	87.0 (10.1)	68.4 (10.1)*	70.1 (10.4)
Role function physical	61.9 (13.0)**	82.4 (14.0)	72.1 (15.5)	73.4 (15.0)
Emotional function	76.3 (16.0)	80.8 (17.0)	72.6 (15.6)	70.8 (16.2)
Mental health	63.9 ( 8.4)	72.4 ( 7.2)	60.0 ( 9.8)	62.9 ( 9.1)
Energy / Fatigue	54.2 (10.1)	63.4 (10.5)	52.8 (10.1)	57.2 ( 8.8)
Pain	66.6 (11.0)	78.4 ( 9.8)	71.0 (11.2)	72.0 (11.0)
General health perception	60.8 ( 9.0)	72.0 ( 9.3)	67.3 (10.2)	70.3 ( 9.6)

Standard deviations are shown in brackets.

\* =  $p < 0.05$  for Crohn's disease vs. healthy volunteers at baseline (t-test).

\*\* =  $p < 0.05$  for psoriatic arthritics vs. healthy volunteers at baseline (t-test).

Table 8.4

Mean SF36 scores for Crohn's disease patient group

n = 25	Baseline	Six months	Twelve months
Physical function *	70.0 (8.8)	71.2 (3.2)	70.4 (3.0)
Physical function	71.2 ( 8.7)	72.2 (8.9)	71.8 (9.3)
Social function *	67.6 (10.4)	69.6 (9.9)	68.2 (9.8)
Social function	69.2 (10.2)	70.6 (11.0)	69.0 (9.8)
Role function physical *	72.5 (12.2)	72.9 (11.7)	70.3 (12.1)
Role function physical	71.8 (13.1)	74.0 (13.6)	72.8 (13.4)
Emotional function *	74.0 (15.0)	78.0 (13.9)	75.2 (14.1)
Emotional function	71.2 (14.4)	72.6 (14.1)	72.6 (14.0)
Mental health *	58.7 (10.1)	68.7 (11.6) <sup>+</sup>	60.7 (11.4)
Mental health	61.2 (10.3)	65.2 (10.6)	62.2 (10.2)
Energy/Fatigue *	54.0 (10.4)	55.1 (12.2)	54.8 (12.1)
Energy/Fatigue	51.6 (10.2)	52.0 ( 9.4)	50.6 (10.8)
Pain *	70.9 ( 9.4)	73.4 ( 9.9)	72.1 (10.7)
Pain	71.1 ( 9.7)	72.4 (10.8)	72.3 (10.9)
General health perception *	67.4 (10.2)	67.1 (10.7)	68.4 (10.8)
General health perception	67.2 ( 9.7)	67.4 (10.8)	67.1 (10.8)

\* = active counselling.

Standard deviations are shown in brackets.

<sup>+</sup> = p<0.05 for improvement in score at 6 months (t-test).

Table 8.5

Mean SF36 scores for ulcerative colitis patients

n = 25	Baseline	Six months	One year
Physical function *	76.1 (8.4)	78.2 (9.3)	78.4 (8.9)
Physical function	75.2 (8.3)	75.4 (9.1)	77.2 (9.2)
Social function *	71.0 (9.7)	71.4 (10.9)	71.6 (10.8)
Social function	69.2 (9.5)	68.6 (11.6)	72.4 (10.9)
Role function physical *	72.4 (11.9)	73.4 (12.1)	72.8 (12.4)
Role function physical	74.3 (12.4)	74.6 (13.1)	73.8 (12.1)
Emotional function *	71.0 (13.6)	73.0 (12.4)	72.6 (11.3)
Emotional function	70.6 (13.8)	74.0 (11.7)	73.6 (12.0)
Mental health *	61.4 (9.8)	69.2 (9.1)	68.0 (10.8)
Mental health	64.4 (9.9)	65.4 (10.7)	66.2 (10.6)
Energy/Fatigue *	57.2 (10.0)	61.2 (10.1)	60.8 (12.3)
Energy/Fatigue	57.1 (9.4)	61.4 (9.1)	66.2 (10.6)
Pain *	70.8 (8.7)	72.0 (9.2)	60.8 (10.3)
Pain	73.2 (8.8)	71.6 (8.6)	61.4 (9.7)
General health perception *	69.4 (9.2)	68.4 (8.7)	71.1 (10.8)
General health perception	71.2 (9.4)	71.0 (9.6)	73.2 (10.7)

\* = active counselling.

Standard deviations are shown in brackets.

### *Psychological assessment*

Psychological assessment was carried out using three questionnaires; the Hospital Anxiety and Depression score (HAD), Styles and Strategies (SS) and Attitudes and Preferences (AP) questionnaires.

#### *Hospital Anxiety and Depression score*

Baseline assessment of HAD scores demonstrated significantly higher anxiety scores in Crohn's disease patients than in ulcerative colitis patients, psoriatic arthritis patients and healthy volunteers. These differences are shown in Table 8.6. ANOVA demonstrated that there was a significant difference between at least two of the groups at baseline and this was followed up by between group t-tests applying the Bonferroni method of determining statistical significance.

At six months, a significant improvement in mean anxiety scores for Crohn's disease patients was demonstrated and this is displayed in Figure 8.2. Improvement occurred equally in both groups who received active counselling and in those who received general support and was sustained at twelve months but MANOVA (Table 8.7) showed that there was no significant difference between groups.



Table 8.6

Mean HAD anxiety scores for all patient groups

	n	Baseline	Six months	Twelve months
Crohn's disease*	25	9.84 (4.1) <sup>†▲</sup>	7.12 (3.5)	6.44 (3.4)
Crohn's disease	25	10.24 (3.5) <sup>†▲</sup>	8.08 (3.7)	8.68 (3.5)
Ulcerative colitis*	25	7.60 (3.5)	6.72 (3.4)	7.52 (3.5)
Ulcerative colitis	25	7.76 (4.4)	6.68 (4.2)	7.40 (4.3)
Psoriatic arthritis	28	7.28 (2.6)	**	**
Healthy volunteers	50	6.86 (3.5)	**	**

\* = Active counselling.

Standard deviations in brackets.

† =  $p < 0.01$  for Crohn's disease patients vs. healthy volunteers (unpaired t-test).

▲ =  $p < 0.05$  for Crohn's disease scores at baseline vs. six and twelve months (unpaired t-test).

\*\* = not followed up at six and twelve months.



Figure 8.2 Mean HAD anxiety scores for Crohn's disease patients receiving active counselling and general support

Table 8.7

Comparison of HAD anxiety scores in Crohn's disease patients (treatment vs. control group) at baseline, six months and one year

Source of variation	DF	F	Sig of F
TIME	1	47.6	<0.001
TREATMENT GROUP BY TIME	1	0.6	0.43

MANOVA of data for Crohn's disease patients in Figure 8.2 (n = 25)

There was no significant change in the mean scores recorded by ulcerative colitis patients throughout the study (Figure 8.3).

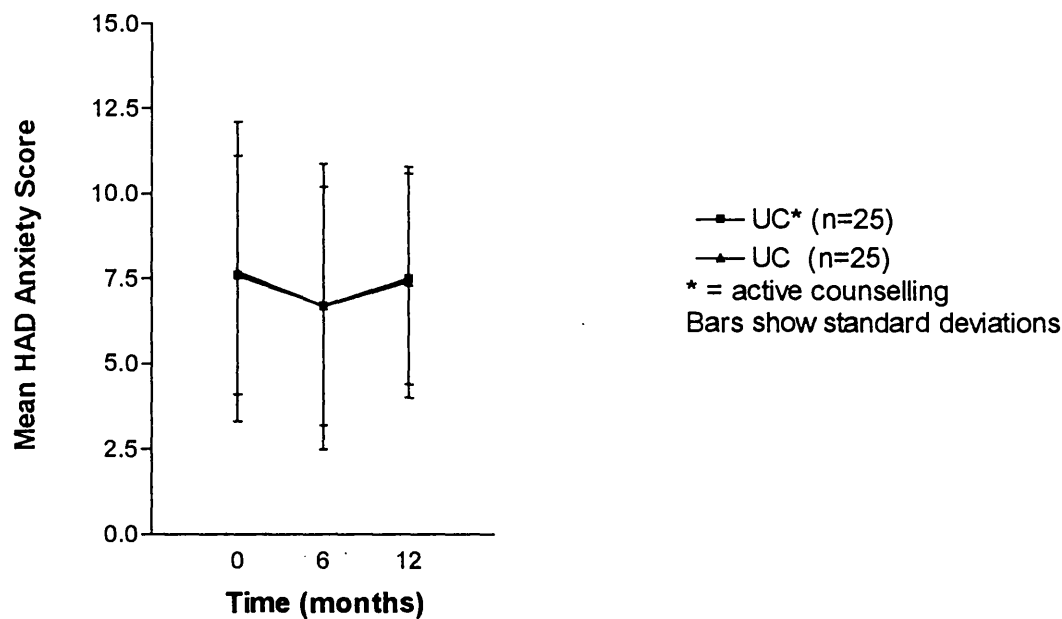


Figure 8.3 Mean HAD anxiety scores for ulcerative colitis patients receiving active counselling and general support

Scores for depression were normal in all study groups throughout the study and no difference was observed between the treatment and control groups in either disease category (Table 8.8). A score of 8 or greater is considered abnormal.

Table 8.8

Mean HAD depression scores for all patient groups

	n	Baseline	Six months	Twelve months
Crohn's disease*	25	5.20 (3.3)	5.28 (3.6)	4.96 (3.5)
Crohn's disease	25	5.80 (4.0)	4.76 (3.4)	5.44 (3.6)
Ulcerative colitis*	25	3.48 (3.0)	3.24 (2.9)	3.44 (3.1)
Ulcerative colitis	25	3.20 (2.9)	3.32 (3.3)	3.00 (3.1)
Psoriatic arthritis	28	5.25 (2.8)	**	**
Healthy volunteers	50	3.82 (3.0)	**	**

\* = active counselling.

Standard deviations are shown in brackets.

\*\* = not followed up at six and twelve months.

*Styles and Strategies*

Normal scores were recorded throughout the study for the adaptive coping scales (Detached and Rational) of the SS questionnaire (Tables 8.9, 8.10 & 8.11).

Normal scores for SS questionnaire are as follows: Rational coping =19, Detached coping =13, Emotional coping =15, Avoidance coping =15, Total Adaptive = 16, Total Maladaptive =15.

Table 8.9

Mean Styles and Strategies scores for control groups

	Psoriatic arthritis	Healthy volunteers
n	28	50
Rational coping	13.5 (6.71)	12.4 (5.45)
Detached coping	14.2 (4.80)	15.5 (4.80)
Emotional coping	13.4 (5.70)	10.1 (4.20)
Avoidance coping	13.6 (4.80)	12.9 (5.10)

Standard deviations are shown in brackets.

Table 8.10

Mean Styles and Strategies Score for Crohn's disease

	Baseline	Six Months	Twelve months
Detached Coping *	13.84 (5.7)	14.04 (5.3)	13.88 (5.2)
Detached Coping	15.04 (4.4)	14.48 (3.9)	14.21 (4.1)
Rational Coping *	18.92 (7.5)	18.68 (7.1)	19.24 (7.2)
Rational Coping	19.68 (6.0)	18.72 (5.3)	18.58 (5.7)
Emotional Coping *	19.88 (2.8) <sup>†</sup>	13.00 (5.5)	11.28 (5.4)
Emotional Coping	19.72 (3.3) <sup>†</sup>	12.16 (5.2)	13.42 (4.9)
Avoidance Coping *	18.20 (4.1) <sup>†</sup>	14.75 (4.4)	14.12 (4.6)
Avoidance Coping	19.04 (5.0) <sup>†</sup>	15.48 (5.8)	15.72 (5.6)
Adaptive Coping *	15.58 (6.9)	16.94 (5.8)	16.56 (5.7)
Adaptive Coping	17.36 (4.7)	16.82 (4.1)	16.39 (4.2)
Maladaptive Coping *	19.04 (3.1) <sup>†</sup>	13.79 (4.3)	12.70 (4.4)
Maladaptive Coping	19.38 (3.7) <sup>†</sup>	13.82 (4.5)	14.58 (4.3)

\* = active counselling.

n = 25

Standard deviations shown in brackets.

† = p < 0.05 for baseline vs. 6 month assessment (t-test).

Table 8.11

Mean Styles and Strategies score for ulcerative colitis

	Baseline	Six Months	Twelve months
Detached Coping *	13.36 (5.4)	14.35 (6.1)	14.08 (5.8)
Detached Coping	13.96 (6.0)	13.80 (6.1)	14.21 (5.7)
Rational Coping *	19.80 (5.3)	20.17 (5.2)	19.28 (5.4)
Rational Coping	18.76 (5.7)	18.42 (5.7)	19.16 (5.6)
Emotional Coping *	12.20 (4.4)	10.33 (5.6)	10.24 (4.6)
Emotional Coping	13.44 (6.4)	11.24 (4.6)	11.00 (6.3)
Avoidance Coping *	14.44 (4.9)	12.75 (6.2)	13.52 (5.2)
Avoidance Coping	15.56 (4.6)	14.64 (5.5)	13.80 (4.8)
Adaptive Coping *	16.64 (4.9)	17.22 (5.6)	16.68 (5.1)
Adaptive Coping	16.36 (5.5)	16.29 (4.9)	16.77 (5.2)
Maladaptive Coping *	13.32 (3.8)	11.12 (4.9)	11.88 (4.4)
Maladaptive Coping	14.50 (4.7)	12.94 (4.6)	12.40 (4.4)

\* = active counselling.

n = 25

Standard deviations are shown in brackets.



Ulcerative colitis patients, psoriatic arthritis patients and healthy volunteers did not display maladaptive coping strategies (Emotional and Avoidance) throughout the study.

Crohn’s disease patients consistently scored significantly higher in maladaptive scales than the other study groups at baseline (Table 8.12 & 8.13). At six months a similar improvement occurred in mean maladaptive coping scores in all Crohn’s disease patients regardless of whether they received active counselling or general support. (Figure 8.4, Tables 8.14 and 8.15) This improvement was sustained over twelve months.

Table 8.12  
Comparison of mean emotional coping scores at baseline

Patient Group	Mean score	factor n	F	Degree of freedom	p
Crohn’s disease	19.80	50			
Ulcerative colitis	12.82	50			
Healthy volunteers	10.12	50	66.15	2	0.0001

ANOVA used as statistical test.

Table 8.13

Comparison of mean SS avoidance scores at baseline

Patient group	Mean score	factor n	F	Degrees of freedom	p
Crohn's disease	18.62	50			
Ulcerative colitis	15.00	50			
Healthy volunteers	12.98	50	17.49	2	0.0001

ANOVA used as statistical test.

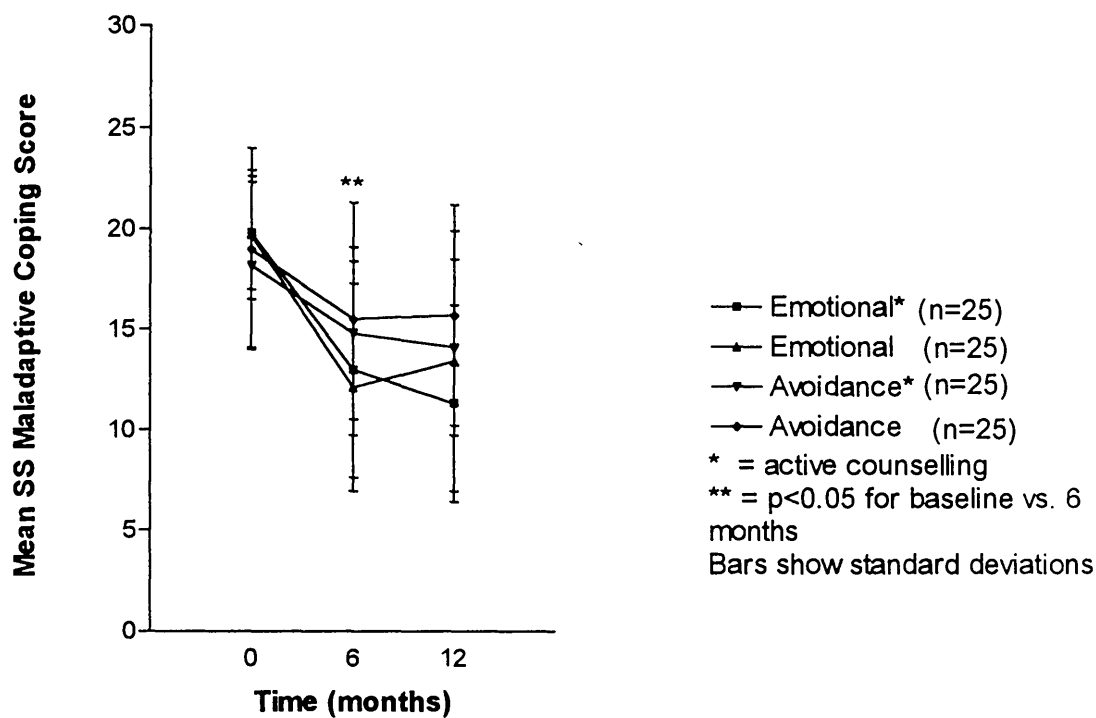


Figure 8.4 Mean SS maladaptive coping scores for Crohn's disease patients receiving active counselling and general support

Table 8.14

Comparison of SS emotional coping scores in Crohn’s disease patients (treatment vs. control group) at baseline, six month and one year follow-up.

Source of Variation	DF	F	Sig of F
TIME	1	76.5	0.00
TREATMENT GROUP BY TIME	1	0.17	0.69

MANOVA of data for Crohn’s disease patients in Figure 8.4 (n = 25).

Table 8.15

Comparison of SS avoidance scores in Crohn’s disease patients (treatment vs. control group) at baseline, six months and one year.

Source of Variation	DF	F	Sig of F
TIME	1	34.2	0.00
TREATMENT GROUP BY TIME	1	0.1	0.85

MANOVA of data for Crohn’s disease patients in Figure 8.4 (n =25).

*Attitudes and Preferences*

Throughout the study mean normal range values were scored for all patient groups and no differences were observed between the treatment and control groups in either disease category (Table 8.16, 8.17 & 8.18).

Normal scores for AP questionnaire are as follows: Rehearsal = 6, Emotional Inhibition = 6, Tolerance for Ambiguity = 5, Locus of Control = 7, Type A Personality = 6.

Table 8.16

Mean Attitudes and Preferences scores for control groups

	Psoriatic Arthritis	Healthy volunteers
n	28	50
Rehearsal	5.36 (2.1)	6.98 (2.3)
Emotional inhibition	5.77 (2.0)	6.32 (2.2)
Locus of control	5.90 (2.1)	7.22 (2.2)
Tolerance for ambiguity	6.20 (1.8)	7.10 (2.0)
Type-A personality	5.18 (1.9)	7.06 (1.9)

Standard deviations are shown in brackets.

Table 8.17

Mean Attitudes and Preferences score for patients with Crohn's disease

	Baseline	Six months	25	Twelve months
n	25			25
Rehearsal *	6.52 (2.2)	7.64 (2.0)		7.50 (2.2)
Rehearsal	7.16 (2.3)	7.20 (2.3)		7.13 (2.3)
Emotional Inhibition *	6.44 (2.1)	6.52 (3.2)		6.52 (2.9)
Emotional Inhibition	7.00 (2.2)	6.87 (2.8)		6.43 (2.6)
Locus of control *	7.36 (1.6)	6.28 (2.3)		6.40 (1.9)
Locus of control	7.36 (2.4)	6.04 (2.6)		6.13 (2.4)
Tolerance for ambiguity *	5.80 (1.8)	6.04 (1.6)		6.80 (2.2)
Tolerance for ambiguity	6.88 (2.2)	6.21 (1.8)		6.56 (2.1)
Type A personality *	6.16 (2.2)	5.88 (2.6)		5.48 (2.3)
Type A personality	6.16 (2.3)	5.60 (2.1)		5.30 (2.2)

\* = active counselling.

Standard deviation are shown in brackets.

Table 8.18

Mean Attitudes and Preferences score for ulcerative colitis patients

	Baseline	Six months	Twelve months
n	25	25	25
Rehearsal *	7.44 (2.4)	7.24 (2.8)	6.56 (2.4)
Rehearsal	7.12 (2.0)	8.08 (2.6)	6.88 (2.4)
Emotional Inhibition *	7.12 (1.8)	7.58 (2.5)	7.20 (2.3)
Emotional Inhibition	5.50 (2.1)	6.34 (3.2)	6.76 (2.8)
Locus of control *	6.80 (1.8)	6.91 (2.6)	7.08 (2.2)
Locus of control	7.36 (1.7)	5.96 (2.0)	6.45 (1.9)
Tolerance for ambiguity *	6.40 (1.8)	5.56 (1.8)	6.16 (2.1)
Tolerance for ambiguity	6.32 (2.1)	6.20 (1.9)	6.87 (1.9)
Type A personality *	6.64 (1.8)	5.72 (2.9)	5.42 (2.4)
Type A personality	6.29 (1.8)	6.28 (2.4)	5.62 (2.2)

\* = Active counselling.

Standard deviation are shown in brackets.

### *Life Events*

Life events subjectively recorded by participants in the month leading up to each assessment are presented in Tables 8.19 and 8.20. At baseline the Crohn's disease patients group reported a mean of 2.86 positive life events and 2.4 negative life events. There was a similar mean number in ulcerative colitis patients (2.88 positive events and 2.42 negative events), psoriatic arthritis patients (2.33 positive events and 2.60 negative events) and healthy volunteers (2.52 positive events and 1.92 negative events), with no significant differences between the groups. At six and 12 months the mean number of reported life events did not significantly change .

Table 8.19

#### Mean number of positive life events reported in all groups

	n	Baseline	Six months	Twelve months
Crohn's disease *	25	3.92 (2.8)	2.52 (2.3)	2.76 (2.3)
Crohn's disease	25	2.56 (2.4)	2.36 (2.1)	2.96 (2.2)
Ulcerative colitis *	25	2.68 (1.9)	2.52 (2.2)	2.44 (2.1)
Ulcerative colitis	25	1.96 (1.7)	1.84 (2.0)	2.36 (1.9)
Psoriatic arthritis	28	2.30 (1.9)	**	**
Healthy volunteers	50	2.52 (1.8)	**	**

\* = active counselling.

\*\* = not followed up at six and twelve months.

Standard deviations are shown in brackets.



Table 8.20

Mean number of negative life events reported in all groups

	n	Baseline	Six months	Twelve months
Crohn's disease *	25	3.16 (0.45)	2.12 (0.28)	2.80 (0.47)
Crohn's disease	25	2.52 (0.31)	2.08 (0.29)	2.96 (0.39)
Ulcerative colitis *	25	3.08 (0.35)	2.52 (0.37)	2.64 (0.52)
Ulcerative colitis	25	2.52 (0.36)	2.12 (0.41)	2.20 (0.43)
Psoriatic arthritis	28	2.60 (0.34)	**	**
Healthy volunteers	50	1.92 (0.34)	**	**

\* = active counselling.

\*\* = not followed up at six and twelve months.

Standard deviations are shown in brackets.

*Interrelationship of variables*

The relationship between the scales employed were initially studied using a correlation matrix. A correlation matrix is a two dimensional display showing the correlation coefficients between all combinations of interest. The relationship between the items of all scales employed were studied and data are shown in Appendices 10 & 11. Selected variables are presented in Tables 8.21 and 8.22. Correlations greater than 0.3 are highlighted in bold as these indicate moderate to good relationships (Knapp, 1978). In Crohn's disease the disease specific component of the IBD questionnaire (DIS) correlated well with the information component of the IBD questionnaire (INFO) and CDAI score (Table 8.21).

Table 8.21

Correlation matrix of selected variables at baseline in Crohn's disease

	Had anx	Had dep	SS em	SS av	CDAI	DIS	INFO
Had anx	1.0						
Had dep	<b>0.45</b>	1.0					
SS em	<b>0.36</b>	-0.07	1.0				
SS av	<b>0.30</b>	-0.05	<b>0.58</b>	1.0			
CDAI	0.24	<b>0.37</b>	0.04	<b>-0.320</b>	1.0		
DIS	0.16	<b>0.55</b>	0.23	-0.11	<b>0.52</b>	1.0	
INFO	0.02	0.20	0.22	0.13	0.17	<b>0.38</b>	1.0

In ulcerative colitis patients there was moderate correlation between DIS and both components of the HAD scale, emotional coping and CDAI score (Table 8.22).

Table 8.22

Correlation matrix of selected variable at baseline in ulcerative colitis

	Hadanx	Haddep	SS em	SS av	CDAI	DIS	INFO
Hadanx	1.0						
Haddep	0.46	1.0					
SS em	0.65	0.26	1.0				
SS av	0.19	0.05	0.42	1.0			
CDAI	0.42	0.13	0.45	0.16	1.0		
DIS	0.40	0.43	0.30	-0.02	0.30	1.0	
INFO	0.11	-0.04	0.31	-0.01	-0.08	0.02	1.0

For Tables 8.21 and 8.22 Hadanx = HAD anxiety score, Haddep = HAD depression score, SSem = Styles and Strategies emotional coping, SSav = Styles and Strategies avoidance coping, CDAI = Crohn’s disease activity index, DIS disease specific component of IBD questionnaire and INFO = information component of IBD questionnaire.

These variables which were used in the Disease specific questionnaire (DIS and INFO) are presented in the next section.

### 8.3 Formulation of a disease specific questionnaire

*Exploratory factor analysis;* In principal components analysis there are initially as many factors as there are variables, in this instance 15. The criterion of Eigenvalues greater than one was used to determine the number of putative factors. In this study principal components analysis followed by oblique rotation revealed that a simple structure was not achieved within the set of variables (see Chapter Six, Table 6.6) and the loadings on questions 6 and 15 suggested a better solution could be derived by omitting these variables from the analysis. Question 6 related to joint pain, which is an extra-intestinal manifestation of IBD and question 15 may have been misinterpreted by subjects due to the ambiguity that surrounds the term “quality of life”. The issues related to HRQOL are addressed in Q12, Q13 and Q14. In this study the rotation which yielded the highest loadings on the relevant factors and the lowest loadings on the other two is presented in Table 8.24. The derived solution obtained by oblique rotation suggests that variables Q3, Q7, Q8, Q9, Q10, Q11 load on factor 1, Q4, Q5, Q12, Q13, Q14 load on factor 2 and Q1 and Q2 load on factor 3. On the basis of the literature review of previous work in this area, suggested names for these three factors given in Table 8.23.

Table 8.23

Cronbach's alpha of disease specific factors.

Named Factors	Cronbach's alpha
Factor 1 (Bowel Specific)	0.8597
Factor 2 ( Non-bowel Disease Specific)	0.7915
Factor 3 (Information)	0.5534

Table 8.24

Principal components analysis followed by oblique rotation of the data obtained from the disease specific questionnaire in Table 6.6

Question	Communality	Factor 1	Factor 2	Factor 3
Q14	.67763	<b>.81063</b>	-.02513	-.00644
Q13	.58099	<b>.77485</b>	-.03459	-.00644
Q12	.53196	<b>.70222</b>	.03533	-.07797
Q 4	.53851	<b>.63994</b>	-.11325	.09831
Q 5	.52931	<b>.58052</b>	-.00014	.03166
Q10	.68700	.11949	<b>.86036</b>	-.13033
Q8	.78184	-.05021	<b>.84593</b>	.18187
Q9	.69498	.02281	<b>.83296</b>	-.03189
Q7	.76518	.07237	<b>-.80036</b>	-.17320
Q11	.71426	-.15341	<b>.77793</b>	-.16699
Q3	.60982	.36245	<b>-.40848</b>	-.11430
Q2	.71686	-.19325	-.02858	<b>-.83120</b>
Q1	.67842	.20479	.05129	<b>-.78741</b>

The loadings of variables on each of the factors which are greater than 0.4 are shown in bold. The derived solution was obtained by oblimin procedure in SPSS PC+. Variables Q6 and Q15 have been omitted from the above analysis. The

communality is the total variance accounted for by the combination of all common factors.

#### *Results of disease specific questionnaire*

Baseline assessment of IBD patients resulted in the identification of bowel activity, disease specific and information provision factors.

#### *Factor 1 Bowel activity*

Impaired bowel control was reported in over two-thirds of Crohn's disease patients and 40% of ulcerative colitis patients. The impact of incomplete bowel control was greater in Crohn's disease, with 54% reporting incidents of faecal incontinence and 64% of patients suffering from faecal urgency (Table 8.25).

Table 8.25

Patient responses to bowel function questions ( Factor 1 )

Question and response.	Crohn's	Ulcerative	Psoriatic
n	Disease	colitis	Arthritis
	50	50	28
Do you have full control over your bowel function ? No	34 (68)	20 (40)	2 (7)
Do you ever have accidents related to control of your bowels ? Yes	27 (54)	14 (28)	1 (3.5)
Do you ever have to rush to the toilet ? Yes	32 (64)	21 (42)	2 (7)
Does your bowel function effect; your recreational activities ? Yes	25 (50)	7 (14)	2 (7)
Does your bowel function effect : your relationships at home ? Yes	21 (42)	14 (28)	0 (0)
Percentages shown in brackets.			

In association with established physical disease assessment patients were asked to provide a subjective assessment of several symptoms commonly associated with IBD. Responses are presented in Table 8.26.



Table 8.26

Physical symptoms reported by patient groups at baseline assessment

(n)	Crohn's disease (50)	Ulcerative colitis(50)	Psoriatic arthritis (28)
Diarrhoea	41 (82)	28 (56)	2 (7)
Abdominal Pain	38 (76)	33 (66)	2 (7)
Tiredness	50 (100)	42 (84)	15 (54)
Joint Pain	36 (72)	25 (50)	27 (96)

Percentages shown in brackets.

Each of these symptoms were given a graded response ranging from 0 (symptom not present) increasing to 3 (symptom severe) and Tables 8.27, 8.28, 8.29 & 8.30 demonstrate the breakdown of these responses. Diarrhoea was present in 82% of Crohn's disease patients on initial assessment, with 32% of patients reporting its severity to be mild, a further 32% as moderate and 18% of patients classified the symptom as severe. It was not as prevalent in ulcerative colitis patients, 44% reported no diarrhoea and, of those who reported the symptom, 38% graded it mild, 14% moderate and 4% severe. Ninety three percent of psoriatic arthritics reported no symptoms diarrhoea (Table 8.27).

Table 8.27

Patients reporting symptom of diarrhoea at baseline assessment

	n	None	Mild	Moderate	Severe
Crohn's disease	50	9 (18)	16 (32)	16 (32)	9 (8)
Ulcerative colitis	50	22 (44)	19 (38)	7 (14)	2 (4)
Psoriatic arthritis	28	26 (93)	2 (7)	0	0

Percentages shown in brackets.

Abdominal pain was present in 76% of Crohn's disease patients, 44% of ulcerative colitis patients and 7% of psoriatic arthritics. There was no significant difference in the severity of abdominal pain reported within the IBD patient groups with the majority of patients reporting mild to moderate pain (Table 8.28)

Table 8.28

Patients reporting symptom of abdominal pain at baseline assessment

	n	None	Mild	Moderate	Severe
Crohn's disease	50	12 (24)	17 (34)	12 (24)	9 (18)
Ulcerative colitis	50	17 (34)	20 (40)	11 (22)	2 (4)
Psoriatic arthritis	28	26 (93)	1 (3.5)	1 (3.5)	0

Percentages shown in brackets.

Tiredness was present in all Crohn’s disease patients, with a quarter of these reporting severe tiredness. Eighty four percent of ulcerative colitis patients complained of tiredness and approximately a half of psoriatic arthritis patients found fatigue a problem as shown in Table 8.29.

Table 8.29

Patients reporting symptom of tiredness at baseline assessment

	n	None	Mild	Moderate	Severe
Crohn’s disease	50	0	16 (32)	21 (42)	13 (26)
Ulcerative colitis	50	8 (16)	20 (40)	17 (34)	5 (10)
Psoriatic arthritis	28	13 (47)	7 (25)	8 (28)	0

Percentages shown in brackets.

Joint pain, which is an extraintestinal manifestation of IBD, was present in 72% of Crohn’s disease patients and half of the ulcerative colitis patients. Table 8.30 illustrates the high level of joint pain suffered by psoriatic arthritic patients.

Table 8.30

Patients reporting symptom of joint pain at baseline assessment

	n	None	Mild	Moderate	Severe
Crohn's disease	50	14 (28)	22 (44)	11 (22)	3 (6)
Ulcerative colitis	50	25 (50)	15 (30)	12 (14)	3 (6)
Psoriatic arthritis	28	1 (4)	10 (36)	11 (39)	6 (21)

Percentages shown in brackets.

*Factor 2 Disease specific*

Responses to those questions which constituted the disease specific factor are presented in Table 8.31. These were graded for each item : 0 (not at all), 1 (a little), 2 (a lot) and 3 (severely). Percentage breakdown of these responses are shown in Tables 8.32, 8.33, 8.34.

Within the disease specific questionnaire a single question asked “ Do you feel your overall quality of life is impaired by your disease ?”. Patients in all disease groups stated that overall quality of life was impaired by the presence of chronic illness. Eighty two percent of Crohn's disease patients, 66 % of ulcerative colitis and 75 % of psoriatic arthritic patients reported at home, socially and at work (Table 8.32).

Table 8.31

Patients response to disease specific questions (Factor 2)

	Crohn's disease	Ulcerative colitis	Psoriatic arthritis
n	50	50	28
Does you feel your overall quality of life is			
impaired by your disease ? Yes	41 (82)	33 (66)	21 (75)
Does it affect your home life ? Yes			
	34 (68)	29 (58)	9 (32)
Does it affect your participation in			
recreational activities ? Yes	41 (82)	21 (42)	22 (78)
Does it affect your occupational lifestyle ?			
	26 (52)	12 (24)	5 (17)

Percentages shown in brackets.

Table 8.32

Patient response question “Is overall ‘quality of life’ affected by your disease ?”

	n	No	A little	Moderately	Severely
Crohn’s disease	50	9 (18)	19 (38)	16 (32)	6 (12)
Ulcerative colitis	50	17 (34)	24 (48)	9 (18)	0
Psoriatic arthritis	28	7 (25)	11 (39)	8 (29)	2 (7)

Percentages shown in brackets.

Table 8.33

Patient response to question “Has disease affected relationships at home ?”

	n	No	A little	Moderately	Severely
Crohn’s disease	50	16 (32)	18 (36)	14 (28)	2 (4)
Ulcerative colitis	50	29 (58)	14 (28)	7 (14)	0
Psoriatic arthritis	28	20 (69)	3 (10)	3 (10)	2 (7)

Percentages shown in brackets.

Table 8.34

Patient response to question “Do you feel your recreational activities are restricted by your disease ?”

	n	No	A little	Moderately	Severely
Crohn’s disease	50	9 (18)	22 (44)	15 (30)	4 (8)
Ulcerative colitis	50	21 (42)	17 (34)	9 (18)	3 (6)
Psoriatic arthritis	28	6 (21)	3 (11)	7 (25)	12 (43)

Percentages shown in brackets.

The mean scores for the disease specific factors are presented in Table 8.35.

Crohn’s disease scores were generally higher than those for ulcerative colitis, although statistically insignificant. Similar improvement was seen in both IBD patient groups during the trial, although this was also insignificant.

Table 8.35

Mean Disease Specific Factor Scores for IBD patient groups

	Baseline	Six month	One year
Crohn’s disease *	7.2 (2.6)	5.7 (2.8)	5.2 (3.7)
Crohn’s disease	7.0 (3.6)	5.8 (2.5)	5.1 (2.4)
Ulcerative colitis *	5.0 (2.7)	4.7 (2.6)	4.6 (2.6)
Ulcerative colitis	4.5 (2.5)	4.2 (3.5)	3.9 (3.5)

\* = active counselling.

Standard deviations in brackets.

*Factor 3 Information Provision*

The third factor identified related to the information provision of information in IBD. The responses to these questions are presented in Table 8.36.

Table 8.36

Patients responses to information variables (Factor 3)

Question;	Crohn's	Ulcerative	Psoriatic
	disease	colitis	arthritis
n	50	50	28
Q1 do you feel that sufficient information			
was given to you about your disease ? No	22 (44)	21 (42)	13 (46)
Q2 Are you familiar with the support group			
for your disease( i.e NACC) ? No	14 (28)	15 (30)	6 (22)

Percentages are shown in brackets.

Table 8.37 presents the results recorded in relation to the provision of information in IBD and psoriatic arthritis.



Table 8.37

Mean Information Factor Score for IBD patient groups

n = 25	Baseline	Six months	One year
Crohn's disease *	2.84 (0.77)	2.16 (0.31)	2.08 (0.28)
Crohn's disease	2.52 (0.86)	2.05 (0.44)	2.00 (0.22)
Ulcerative colitis *	2.81 (0.87)	2.00 (0.31)	1.95 (0.24)
Ulcerative colitis	2.64 (0.74)	2.00 (0.31)	1.95 (0.24)

\*  
= active counselling.

Standard deviations in brackets.

With regard to information provision, patients reported greater satisfaction related to the level of information they had received, with only 5% of Crohn's disease and ulcerative colitis patients reporting dissatisfaction with the level information they received.

## **CHAPTER NINE**

### **DISCUSSION**

## 9.1 Introduction

The aim of the study was to examine the impact of a nurse led counselling service upon the HRQOL of IBD patients.

The major conclusions of this thesis are as follows;

1) Physical and psychosocial morbidity are present to differing degrees in patients with Crohn's disease and ulcerative colitis. Diarrhoea, with urgency and faecal incontinence is the most commonly reported physical symptom although tiredness and abdominal pain also commonly occur. Patients with IBD perceive discrimination at work and report restrictions to their social and family life.

2) Crohn's disease patients reported higher anxiety scores (HAD) than patients with ulcerative colitis. Compared with healthy volunteers and a disease control group of patients with psoriatic arthritis, patients with Crohn's disease display maladaptive coping mechanisms in the areas of emotional and avoidance coping. These patients may become over emotional and avoid dealing with some of the implications of their disease and may, as a consequence, develop anxiety.

3) No specific personality type predominates in IBD patients.

4) Provision of a counselling service may be effective in the reduction of anxiety levels and rectification of maladaptive coping strategies in IBD patients. However, as the level of improvement in psychosocial morbidity was similar in both groups of patients receiving a stress management programme and those given general counselling support coupled with information provision, it is questionable whether the '*Challenge to Change*' programme plays a significant role in the management of IBD patients. Difficulty arises in assessment of the

effectiveness of the counselling service as it was not possible to have a proper control group (i.e a group of IBD patients who had no contact with the nurse). These conclusions are based upon results obtained from the study described in this thesis.

## **9.2 Holistic approach to IBD management**

The clinical management of IBD requires significant time and effort on the part of gastroenterologists and associated health professionals, such as nurses and dietitians. Emphasis in care is clearly focused on controlling activity of disease, but disease activity is not always the best predictor of well-being (Turnbull and Vallis, 1995; Gazzard, 1987).

This is not to say that the established measures of physical disease activity such as CDAI are unimportant; disease indices provide the basis for clinicians' assessment and management of IBD. It has, however, been recognised in recent years that more attention should be paid to the assessment of psychosocial factors. Drossman et al. (1990) highlighted the importance of combining physical disease assessment with psychosocial factors because they define different aspects of medical care. Vallis and Turnbull (1992) advocated a 'biopsychosocial' approach to assessment of HRQOL in IBD. This study addressed the broad assessment of both disease specific and psychosocial factors. Within this study a generic health status questionnaire (SF36) and a disease specific questionnaire were employed. The former allowed for comparison of IBD patients with other patient groups of different illnesses, and the latter was

more sensitive to small but clinically meaningful changes within the IBD patient group.

Increasing attention has been paid to the recommendations of HRQOL studies in IBD and the need for psychological support in this patient group is now widely accepted. Schwarz and Blanchard (1990) promoted the use of counselling support in IBD and highlighted the importance of teaching coping strategies care in the management of these patients. There is, however, no evidence to suggest that these psychological interventions improve outcome. This study addresses the impact of a support service upon IBD patients using such psychological interventions. The following sections examine the findings and consider some of the methodological aspects of this study.

### **9.3 Pilot Study**

The aims of the pilot study were to define physical and psychosocial morbidity in a cohort of IBD patients and to test the methods of assessment. The patients were a consecutive selection of out-patients attending a gastrointestinal review clinic with a substantiated diagnosis of Crohn's disease or ulcerative colitis. As out-patients they did not have extremely active disease, although most had required hospitalisation at some stage. Patients had extremely good compliance rates in the pilot study and reported no problems with completion of the assessment scales. The study demonstrated that high levels of anxiety, but not depression, were present in Crohn's disease, whilst patients with ulcerative colitis did not, as a group, demonstrate high levels of anxiety. Medical

practitioners within the unit in which the study was conducted were surprised at the level of social disability that patients reported in association with incomplete control with their bowel function (faecal incontinence and urgency). It was realised by medical staff that the majority of these patients had diarrhoea, but its severity and social consequences were far greater than anticipated. This lack of understanding of the implications of incomplete bowel control may have resulted from the patients not being specifically asked about faecal urgency and incontinence.

Disruption to life at home and work was common despite the fact that many patients recorded low disease activity scores. These findings support Turnbull and Vallis's (1995) recommendations that, for optimum management in IBD, both disease activity and psychosocial assessment are necessary.

Another significant problem highlighted from the pilot study related to the provision of information to IBD patients. Lack of information was commonly cited as a source of anxiety and this has obvious implications for health professionals as information should constitute a basic part of health care provision.

Psychosocial morbidity was greater in Crohn's disease than in ulcerative colitis, supporting the findings of Tarter et al. (1987) and Drossman et al. (1990) who reported poorer health status in Crohn's disease, with greater psychological and social dysfunction in the areas of recreation, rest and work.

Several methodological problems in the pilot study are acknowledged. The study provided only a 'snap-shot' assessment of morbidity in IBD and such

assessments are of limited value when addressing an illness with an unpredictable course. This underlined the need for a longitudinal, prospective approach in the subsequent study.

Furthermore the pilot study was uncontrolled and was performed on a selected group of out-patients who generally had mild disease. With regard to patients' perceptions of IBD causing employment restrictions, it must be stressed that only the patients were questioned and to obtain a true picture of the implications of IBD upon employment it would be appropriate to question employers as well. The questionnaire used to assess disease specific morbidity in the pilot study was undergoing development and was not fully validated. Despite this, the pilot study however provided a cross-sectional profile of physical and psychosocial morbidity and defined areas for subsequent study.

#### **9.4 Prospective study design; possible confounding factors**

The study was designed to measure the impact of a counselling service upon morbidity in IBD patients. Physical and psychosocial morbidity were measured on entry to the study and reassessed six and twelve months after randomisation to either active counselling or general support. Disease and healthy volunteer control groups were assessed in a similar manner at baseline. Those patients who were randomised to receive active counselling were required to attend the out-patient department for implementation of the '*Challenge to Change*' programme and despite the fact all IBD patients were compliant, many questioned the nature or need for psychological intervention. Patients commonly stated that they did

not feel stressed and denied feelings of anxiety. Indeed one patient felt as if he was being treated as if his IBD was 'all in the mind'. It was important to reassure patients that the psychological support provided was supplementary to their medical management and was not an alternative. The implementation of a stress management programme also requires the patient firstly to accept that there is a stress problem and secondly for the patient to be motivated to do something about it.

One particular ethical dilemma arose in patients who reported anxiety as a problem in their lives but who were randomised to receive general supportive care. If included in the study these patients may have benefited from counselling support, yet they were deprived of a potentially beneficial treatment. As a registered nurse, and in line with the United Kingdom Central Council for Nursing and Midwifery (UKCC) Professional Code of Conduct (United Kingdom Central Council, 1992), this dilemma raised the question of professional responsibilities within the clinical trial. In instances of extreme psychological morbidity patients were excluded from participation in the study and were referred to a professional psychologist. There will always be ethical dilemmas when implementing a clinical trial based on the provision of counselling. It is unprofessional for a nurse to deprive a patient of care which may be beneficial, whilst at the same time it is impossible to fully evaluate the impact of a counselling service if patients who are randomised to receive non-active treatment receive psychological support and information from other sources.



All IBD patients received support and information from the research nurse, in addition they were provided with a contact telephone number for the patient support group, NACC. Nichols (1993b) argued that the mere existence of a support network may provide reassurance for patients with illness, regardless of whether they use it. Patients may derive comfort and reassurance simply from the knowledge that someone is taking an interest in their illness. Roesthlisberger and Dickson (1939) highlighted the impact that managers made by taking an interest in a group of factory workers welfare, observed in a study referred to as the Hawthorne experiment. The impact of increased interest from management was to increase the motivation of the workers. Sinclair and Fawcett (1991) described the '*Hawthorne effect*' as directly applicable to the caring professions and the provision of a support service may in itself lead to a improvement in patients well-being.

Rachman and Wilson (1980) reported 'non-therapeutic' experiences in many instances to produce similar results to that of psychological therapy. They found modest evidence to support the beneficial effects of psychotherapy and postulated that people may gain no more than comfort from psychological therapy. This may explain the improvement seen both in patients who received active treatment and those who received general counselling support in this study. The difficulty in establishing the power necessary to detect statistical significance between treatment and non-treatment groups in psychotherapy outcome research is highlighted by Kazdin and Bass (1989).

A further confounding factor may relate to the existence of the support agency NACC, which provides a confidential telephone counselling service, making it impossible to determine whether any patients within this study received additional psychological support (Godber and Mayberry, 1988a). It was recognised that other support sources, such as church and family may also have been available.

An important issue which was considered when implementing the trial was the potential damage which might follow psychological intervention. One such instance arose when a 24 year ulcerative colitis patient was assessed at the out-patient clinic. Unknown to the researcher the patient had a history of psychiatric illness and was openly disturbed at the suggestion that she might require psychological support. In this particular case the patient was referred for psychological assessment and excluded from the study. Whilst there are possible benefits to be gained from a counselling service, it follows that the removal of psychological support at the end of the clinical trial may lead to psychological disturbance. Several patients undoubtedly became dependent upon the support provided in the study and were upset when it was withdrawn at the end of the trial.

A further issue related to the study design was that of gender bias. Support was given by a male researcher to both male and female patients and it is possible that one gender may respond differently to counselling from either a male or a female. However no significant difference was noted between anxiety scores (HAD) between males and females in the patient groups.

Additionally, the fact that assessment and counselling were supervised by the same person within this study raises the possibility of bias. There were several procedures undertaken within this study to prevent such bias occurring, these included the avoidance of leading questions and loaded words within the questionnaires and use of structured interviews.

#### **9.4.1 Follow-up**

During the planning stage of this study three monthly rather than six monthly reassessments over a twelve month period were considered. Frequent assessments would have provided a more accurate assessment of the fluctuating course of the disease and a better picture of ongoing life events. Eventually three monthly assessment was deemed impractical. The short timescale would have provided a workload too great for a single researcher and it was essential to cause minimal disruption to patients' lifestyle. A more frequent review may have caused undue concern and may have led to higher rates of non-compliance and questionnaire fatigue.

Since physical disease activity assessment was in part based upon global assessments by physicians, it would have been ideal for the same clinician to see the patients at each visit, as it could be argued that different clinicians might provide different assessments. It was impossible to use a single clinician because of the rotation of medical staff and clinic arrangements.

The timing of assessment is a possible confounding variable in the measurement of HRQOL. It is known, for example, that Seasonal Affective Disorder (SAD) can affect up to 15% of the population in winter months and it is therefore

possible that patients perceive better HRQOL in the summer months (Rosenthal et al. 1984). This would, of course, have applied to both the actively and generally supported groups.

#### **9.4.2 Subjects**

##### *Inflammatory Bowel Disease*

Sample size in this study was calculated on the basis of a power analysis. Originally it was suggested a sample size of 25 patients per study group would be sufficient to examine a large clinical effect at  $p < 0.05$  (Cohen, 1992). However, due to the difficulty in establishing differences between the treatment and non-treatment groups, where both are receiving some degree of support a larger sample size is recommended to detect small/medium changes in effect outcome.

No patients were lost from the study and compliance was excellent. IBD patients proved to be a highly motivated and compliant patient group, who reliably attended out-patients and conscientiously completed questionnaires. Indeed, no patient refused or withdrew written consent. One reason for this may have been that the researcher had worked in the unit for several years and was well known to the patients. It may be argued that patients were constrained to comply with the study because they were dependent upon the health care team responsible for the management of their illness. There were examples of the 'popular patient' as described by Stockwell (1972). To overcome this, it was stressed to all recruits that psychological care given within the study was supplementary to their medical treatment and that they were free to participate or withdraw from the

study at any stage. Doctors involved in their clinical management were in fact unaware of their involvement in the study.

### *Control Groups*

In a methodologically perfect study similar methods of assessment, counselling and intervention would have been undertaken in both the disease control group and the healthy volunteers. This was not possible for several reasons as follows:

a) Healthy volunteers were selected at random from a local factory workforce.

They provided an ideal control group because they had a similar age and sex distribution as the IBD group. At baseline the healthy volunteers completed all the questionnaires with the exception of the IBD disease specific questionnaire.

For practical reasons these control subjects were not interviewed by the research nurse and because of rapid staff turnover, follow-up assessments were impossible.

b) Recruitment was difficult in the psoriatic arthritic control group. Over 100 patients were identified, screened and contacted via the rheumatology outpatient department, but only a few agreed to be included in the study. This was principally because many arthritic patients have poor mobility and refused to attend a research based clinic, which would provide little personal direct benefit. Those who were employed could not attend the clinic during working hours. Non-participation may also have arisen from the research being conducted in another hospital department, the gastrointestinal unit, rather than the rheumatology department with which they were familiar.

Psoriatic arthritics were considered to be an appropriate disease control group. The disease has many similarities to IBD because it is a chronic inflammatory illness with a relapsing and remitting nature and in many instances drug therapy is comparable. Nevertheless patients with psoriasis may differ from IBD patients because of a potentially disfiguring skin complaint which may have psychological consequences.

#### **9.4.3 Assessment tools**

##### *Crohn's disease activity index*

The CDAI is widely used as a quantitative measure of physical disease activity in Crohn's disease. Despite this, Choudari et al. (1993) criticised the CDAI because it is heavily weighted by factors of general well-being and abdominal pain. Van Hees et al. (1980) were critical of the omission of important objective parameters of inflammatory activity, such as serum albumin level and ESR. Garrett and Drossman (1990b) showed that the CDAI did not correlate with IBD patients' subjective sense of well-being and Mee (1978) believed it to be too cumbersome for use in out-patient departments. Nevertheless the modified CDAI provided quantitative data for both Crohn's disease and ulcerative colitis patients. Questions may be raised over the applicability of a modified CDAI for physical disease assessment in ulcerative colitis. The CDAI has been used to assess physical disease activity in ulcerative colitis by Helzer et al. (1982). Irvine et al. (1996) employed a modified CDAI for validation of the Short Form Inflammatory Bowel Disease Questionnaire. Other than minor problems related to the completion of the diary cards, no significant problems were encountered.

### *Short form 36 (SF36)*

Stewart (1949) perceived health scales as notoriously difficult to measure and the SF36 is no exception as it provides no overall summary scale or single index. Analysis of SF36 data is achieved by comparison with normative data from the general population.

The SF36 is reported to have high levels of reliability, validity and responsiveness in disease free populations. Brazier et al. (1992) suggested that SF36 scores in groups of patients with physical illness should be consistently lower than in normative data provided for the general population and this was indeed found to be the case in both IBD and psoriatic arthritis patients. It is important to stress that the SF36 had not previously been tested in IBD. Although the scale was completed by all study participants its validity in IBD and psoriatic arthritis remains questionable. These potential problems of 'off the shelf' health indices were emphasised by Jenkinson (1993). For example the SF36 includes a thorough assessment of mobility which may be affected in psoriatic arthritis patients but this may not be very important in the assessment of IBD patients. The SF36 contains no variable assessing sleep and this is an important omission as reduction of insomnia was one of the aims of providing stress management therapy; therefore overall health status measurement may be limited in this patient group using SF36 alone.

Further study is therefore required to define the applicability of the SF36 to IBD patients.

### *Disease Specific Questionnaires*

When this study was designed there was no accepted 'gold standard' for measuring quality of life in IBD. The IBDQ was then published and validated as the HRQOL measurement tool of choice. Recent recommendations by Irvine et al. (1996) have highlighted the need for shorter questionnaires which can be easily implemented in out-patient departments. The questionnaire described in this thesis incorporated 15 items based upon disease specific and information variables, described in Chapter Six. Turnbull et al. (1996b) have described a five item questionnaire which is applicable to out-patient departments and is as reliable and sensitive as the 32 item IBDQ.

The questionnaire developed in this study included psychosocial issues which may facilitate clinical care. It is important that emphasis is given to psychological functioning as well as physical factors in the determination of HRQOL.

### *Hospital Anxiety and Depression Scale (HAD)*

The HAD scale is an assessment tool designed specifically for use in patients who are physically ill. It has proved to be very robust across studies and has been shown to be composed of two distinct but correlated factors, anxiety and depression. In this study a score of greater than eight was defined as significantly abnormal (Barczack et al. 1988; Snaith and Taylor, 1985). The HAD scale was useful in the present study and patients stated that they found it easy to understand and complete. One problem area which existed concerned the statement 'I feel as if I am slowed down'. The response most often scored by



patients for this statement was 'nearly all the time'. This response was particularly frequent in those patients with a high CDAI score. Thus it is possible that a positive response to this question might be due to physical disease rather than psychological morbidity. This concern has also been raised by Ibbotson et al. (1988) who questioned the value of HAD in assessment of cancer patients. Andrews et al. (1987) reported that HAD displayed both sensitivity and specificity in the measurement of psychological morbidity in IBD patients.

### *Styles and Strategies*

Patients reported no difficulty and displayed high levels of compliance in completing the SS questionnaire. Maladaptive coping strategies, such as emotional and avoidance coping, were particularly common in Crohn's disease patients and, like HAD anxiety scores, these improved during the course of the study. Patients from both the actively counselled and general support groups improved to the same degree. It is therefore likely that this improvement was unrelated to the intricate psychological techniques outlined in the '*Challenge to Change*' programme but was a consequence of providing patients with information related to their disease and to the existence of a support network. Ethically, it was impossible to blind control IBD patients, as by merely explaining the nature of the SS questionnaire a level of insight into coping strategies is given. Some patients who were motivated to address actively maladaptive coping strategies appeared to derive great personal benefit, although this is not fully reflected in the results. The questionnaire findings were based upon

analysis of the patient group and therefore does not highlight individual cases. This might have been overcome by use of a single case experimental design which can draw conclusions from assessment of individual patients (Newell, 1992).

#### *Attitudes and Preferences*

Patients reported no problems in completing the questionnaire. Throughout the study all patients scores fell within the normal range. This supports the findings of Blanchard and Schwarz (1990) who, in reviewing the literature, showed that the personality profile of IBD patients is similar to that of the general population.

#### **9.4.4 Intervention**

Intervention was based upon two main areas of psychological support, the '*Challenge to Change*' stress management programme, and the provision of information.

##### *I) 'Challenge to change'*

Roger and Nash (1993b) demonstrated the applicability of this programme within occupational groups, such as police and prison officers, but it had not been applied to patients with chronic physical disease. The programme was adapted to minimise inconvenience and disruption of the patient's lifestyle. The key to success of the '*Challenge to Change*' programme is the motivation of the individual to whom it is taught. Each patient must accept that anxiety and stress can potentially disrupt lifestyle and the individual must have the motivation to develop personal skills in coping. Anecdotally, individuals who accepted these

facts and made the choice to undertake the programme found there were certainly benefits to be gained. There can be no doubt that stress does exist and Roger stated that the consequence of ignoring it may well be "a short miserable life" (Roger and Nash, 1993b). A case illustration of this is provided by a 46 year old patient with long-standing ulcerative colitis. She complained of faecal urgency which greatly affected her social activities and derived great benefit from the '*Challenge to Change*' programme. Through devising several coping strategies, with the research nurse, to reduce the risks having accidents, she reported feeling more relaxed about her impaired bowel control, which enabled her to enjoy a better quality of life.

As previously highlighted in this section, there were several problems which were encountered in the implementation of the stress management programme. Many patients who were randomised to receive additional psychological intervention did not see the need for some aspects of psychological intervention, especially the use of relaxation therapy tapes and it is certainly not possible to force someone to relax. It can be concluded, as stated previously, that the '*Challenge to Change*' was only applicable and of benefit to those patients who accepted that stress was a problem within their lives and were motivated to do something about it.

## ii) Provision of information

It is well documented in nursing research literature that lack of information can lead to anxiety and fear in patients. Hayward (1975), in a Ministry of Health

report, highlighted 'some very relevant problems associated with information provision and communication in health care. These are summarised in Table 9.1.

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Table 9.1

Difficulties in information provision and communication in health care

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Inappropriate form and quality of information.

No individual having responsibility for co-ordination of information

'Censored information' i.e depriving patients valuable information.

Unfavourable context of information. i.e information must be given in understandable language, not using medical jargon. It must be comprehensible.

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Within both the pilot study and in the baseline assessment of the main study it was clear that the majority of patients with IBD were dissatisfied with both the level and quality of information they had received about their disease. Patients commonly reported insufficient information regarding their drug therapy, diet and the disease process itself. Nichols (1993a) stated that poorly informed patients are more likely to be stressed and less likely to be compliant with treatment. In the knowledge of the positive impact on understanding and retention of medical information that can be achieved, Ley (1989) provided guidelines which are highlighted in Table 9.2 for delivery of information to patients, relatives and employers. There was generally a positive response to the information package provided to IBD patients, although some patients sought

additional information and reported frustration in cases where questions related to the cause of IBD were not answered.

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**Table 9.2 Guidelines for successful delivery of information in health care**

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- Use of primary effects (i.e people recall best the first few things they are told at one time).
  - Stress the importance of particular items of information.
  - Simplification of language. i.e using shorter words and sentences.
  - Labelling of categories of information. (“now I’m going to tell you about the drugs you will have to take”)
  - Give specific rather than general information.
  - Repetition
  - Provide additional interviews to check patient’s understanding and retention of information.
- 

## **9.5 Conclusion**

Psychosocial morbidity is common in Crohn’s disease and is present to a lesser extent in ulcerative colitis. The work reported here suggests that anxiety scores and maladaptive coping strategies may be improved through the provision of a counselling service. Furthermore, it is probably unnecessary to employ time

consuming stress management techniques, such as the '*Challenge to Change*' programme, since patients receiving general psychological support and information improved to the same degree as those given basic support. Patients who were fully motivated and accepted that they were anxious derived obvious benefits from the programme. In most cases intricate forms of psychological intervention are impractical and unnecessary when patients present with high levels of psychological morbidity and these individuals should be referred for help to a clinical psychologist.

It is a reasonable conclusion that provision of a support network, such as the one provided in this study, may be of benefit to IBD patients, who can suffer tremendous disruption to their lifestyle because of physical and psychosocial morbidity associated with their condition. Such support is provided by NACC, but as this a patient led group it does not involve health professionals. It is believed that more support is required within the health care setting and greater emphasis should be placed on combining the assessment of psychosocial well-being in addition to managing physical disease. This study suggests that nurses may have a potentially important role to play in the physical and psychological management of HRQOL in IBD, not only to sufferers of the condition, but to their family, friends and employers, and in a broader sense, to educate the general public to try to address many of the taboos and stigma that are associated with bowel disease. The study demonstrates that such nursing care is practical and nurses are in the ideal position of having the knowledge and skills to deal with both the physical and psychosocial aspects of chronic illness.

It is relevant to note the recent emergence of clinical nurse practitioners in the field of gastrointestinal nursing. The creation of these posts have been stimulated by the recommendations of the Calman Report, with the need to reduce junior doctors hours of work and the associated role extension within the nursing profession into areas such as counselling (Read, 1995). However it is questionable whether such individuals have the time or expertise to provide the specialist care this patient group requires. It is not simply enough for nurses making the effort to be more caring but a professional scheme of psychological care should be provided. Newly diagnosed IBD patients should routinely have information provided in light of these guidelines.

## **9.6 Further research**

This thesis has generated as many questions as it has answered and it is clear that further research is required in several areas:

More and clearer information is needed to better characterise HRQOL in IBD patients. Differences between the morbidity of Crohn's disease and ulcerative colitis patients needs to be further defined as current assessments do not differentiate between the two. Further assessment of the relationship between disease activity and QOL is required.

Answers to these and other questions may result in the development of more sensitive measures of illness. In particular the development of a short HRQOL assessment tool which is valid, reliable and responsive to important clinical changes would provide great benefits when applied in the primary care setting.

This research suggests that counselling may be a way forward in the treatment of IBD patients, there is however a need for specific research projects addressing topics related to counselling and the risk of cancer and sexual dysfunction. Research in these areas may benefit from the inclusion of the use of a multi-centre design with blind assessors and the inclusion of an IBD patient control group who are blinded from all forms of counselling support.

Future research should give appropriate attention to the importance of power in the evaluation of treatment outcome of psychological intervention in IBD, to ensure that the sample size is sufficiently large enough to detect differences between treatment groups and those patients who receive less treatment, as was the case for control group IBD patients in this study. It was estimated that 50 patients should be randomised into this study to obtain a 40% change in the scoring of SF 36 domains at a significance level of  $p=0.05$ . This issue of power is possibly common to many areas of nursing research, as it is often difficult to isolate a control group of patients who are blinded from all aspects of nursing intervention. Improved study design may also alleviate the difficulties the researcher was under as both the therapist and the observer.

Investigations examining the effect of other forms of psychological intervention, such as, hypnotherapy may throw further light upon the link between stressful life events-symptoms and exacerbation of illness in IBD. This study does suggest that the principle of psychological intervention in IBD warrants further investigation. Psychological treatments should strive to correct some of the deficits which have been highlighted in this thesis. If patients can control some



psychosocial aspects of their the disease, through the use of psychological interventions, this could lead to improved QOL. The direction of psychological treatments should incorporate teaching patients adaptive coping skills for stressful situations, whilst dealing with the physical effects of their ill health.

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## APPENDICES

## APPENDIX 1

### PATIENT PROFILE (CROHN'S DISEASE)

Appendix 1 Crohn's disease: Patient profile.

Patient Number.	Random -ised.	Age	Sex	Extent of Crohns disease	Drugs on recruitment to study.	Surgery
51	No	61	Female	Not specified	Nil	Ileal Resection
52	No	26	Female	Colonic	Prednisolone, azothioprine.	Nil
53	Yes	35	Female	Colonic	Prednisolone, mesalazine.	Nil
54	Yes	25	Female	Rectal	Questran.	R.Hemi
55	Yes	23	Male	Colonic	Prednisolone, mesalazine.	Ileostomy
56	Yes	47	Male	Not specified	Mesalazine.	R.Hemi, II Res
57	Yes	25	Female	Not specified	Coproxamol.	Nil
58	Yes	18	Male	Small bowel	Salazopyrin	Nil
59	Yes	30	Female	Ileo-Colonic	Nil	Nil
60	No	68	Female	Colonic	Prednisolone, mesalazine.	Nil
61	No	24	Female	Small bowel	Prednisolone	Nil
62	Yes	18	Female	Colonic	Pentasa.	Nil
63	Yes	24	Female	Small bowel	Mesalazine.	R.Hemi
64	No	30	Male	Not specified	Azothioprine.	Nil
65	Yes	50	Female	Not specified	Nil	Ileostomy
66	No	64	Female	Colonic	Azothioprine.	Nil
67	Yes	33	Female	Colonic	Azothioprine.	Nil
68	Yes	19	Male	Not specified	Azothioprine.	Nil
69	No	44	Female	Small bowel	Nil	R.Hemi, II Res
70	Yes	22	Male	Sm/Lg bowel	Prednisolone, azothioprine.	Nil
71	No	52	Female	Small bowel	Prednisolone, salazopyrin	Nil
72	Yes	60	Male	Not specified	Mesalazine.	Nil
73	No	28	Male	Colonic	Azothioprine.	Nil
74	No	47	Female	Ileal	Nil	Ileal Res

75	No	51	Female	Small bowel	Mesalazine, azothioprine.	Ileostomy
76	No	31	Female	Ileal	Questran.	R.Hemi, Il Res
77	Yes	18	Female	Colonic	Prednisolone, mesalazine.	Nil
78	No	51	Female	Not specified	Mesalazine.	Nil
79	Yes	49	Male	Not specified	Salazopyrin, questran.	R.Hemi.
80	Yes	34	Female	Colonic	Osalazine.	Nil
81	Yes	52	Male	Colonic	Nil	Ileostomy
82	Yes	54	Female	Not specified	Codeine phosphate.	Colostomy
83	No	37	Male	Ileal	Azothioprine.	Nil
84	No	34	Female	Ileal	Nil	Ileostomy
85	No	64	Female	Ileal	Nil	Nil
86	Yes	28	Female	Ileal	Prednisolone, mesalazine.	Nil
87	Yes	44	Female	Small bowel	Mesalazine.	Il Res
88	Yes	28	Female	Ileo-caecal	Prednisolone.	Nil
89	No	43	Male	Not specified	Nil	Ileostomy.
90	No	17	Male	Small bowel	Mesalazine.	Nil
91	No	53	Female	Colonic	Mesalazine.	Nil
92	No	55	Female	Recto-sigmoid	Sulphasalazine.	Nil
93	No	29	Female	Small bowel	Pentasa.	Il Res
94	Yes	33	Female	Not specified	Cyclosporin.	Nil
95	No	26	Male	Not specified	Salazopyrin, azothioprine.	Nil
96	No	55	Male	Colonic	Salazopyrin.	Nil
97	Yes	28	Male	Colonic	Mesalazine.	Nil
98	Yes	30	Male	Colonic	Mesalazine.	Nil
99	No	55	Female	Colonic	Nil	Nil
100	No	52	Female	Not specified	Nil	Il Res

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## APPENDIX 2

### PATIENT PROFILE (ULCERATIVE COLITIS)

Appendix 2 Patient Profile; Ulcerative colitis.

Patient Number	Randomised	Age	Sex	Extent of UC	Drugs on recruitment to study.	Surgery
101	No	54	Male	distal colitis	Mesalazine.	Nil.
102	Yes	26	Female	pan colitis	Prednisolone, mesalazine.	Nil.
103	Yes	21	Male	pan colitis	Azothioprine, mesalazine.	Nil.
104	Yes	51	Male	not specified	Mesalazine.	Nil.
105	Yes	30	Female	proctitis	Mesalazine.	Nil.
106	Yes	27	Female	distal colitis	Prednisolone, mesalazine.	Nil.
107	No	35	Male	pan colitis	Salazopyrin.	Nil.
108	Yes	51	Male	distal colitis	Prednisolone, azothioprine.	Nil.
109	Yes	49	Male	not specified	Prednisolone, azothioprine.	Nil.
110	No	26	Female	left sided	Mesalazine.	Nil.
111	No	33	Female	not specified	Mesalazine.	Nil.
112	Yes	48	Male	pan colitis	Mesalazine.	Nil.
113	No	17	Male	not specified	Colifoam enemas.	nil.
114	Yes	60	Male	left-sided	Prednisolone, mesalazine.	Nil.
115	No	49	Male	distal colitis	Mesalazine, Colifoam enemas	Nil
116	No	42	Female	not specified	Mesalazine.	Nil
117	Yes	42	Male	not specified	Mesalazine.	Nil
118	No	55	Female	pan colitis	Mesalazine.	Nil
119	No	57	Male	distal colitis	Salaz.	Nil
120	Yes	36	Male	not specified	Mesalazine, prednisolone.	Nil
121	No	46	Male	left-sided	Prednisolone, mesalazine.	Nil
122	No	42	Female	distal colitis	Prednisolone, mesalazine.	Nil
123	No	28	Male	proctitis	Prednisolone, mesalazine.	Nil
124	Yes	47	Male	proctitis	Azothioprine, mesalazine.	Nil



125	No	61	Female	proctitis	Mesalazine.	Nil.
126	No	30	Male	proctitis	Mesalazine.	Nil.
127	Yes	28	Male	not specified	Azothioprine, salazopyrin.	Nil.
128	No	39	Male	distal colitis	Mesalazine.	Nil.
129	No	35	Male	proctitis	Azothioprine.	Nil.
130	Yes	41	Female	left-sided	Mesalazine.	Nil.
131	Yes	34	Female	left-sided	Mesalazine.	Nil.
132	No	32	Female	not specified	Nil.	Nil.
133	No	27	Female	pan colitis	Mesalazine.	Nil.
134	No	47	Female	not specified	Mesalazine.	Nil.
135	No	21	Female	not specified	Mesalazine.	Nil.
136	No	17	Female	pan colitis	Prednisolone, mesalazine.	Nil.
137	Yes	66	Male	proctitis	Salazopyrin.	Nil.
138	Yes	23	Male	distal colitis	Salazopyrin.	Nil.
139	No	52	Male	proctitis	Salazopyrin.	Nil.
140	No	38	Male	not specified	Mesalazine.	Nil.
141	No	33	Male	not specified	Mesalazine.	Nil.
142	Yes	34	Female	not specified	Nil.	Nil.
143	Yes	33	Male	proctitis	Prednisolone, azothioprine.	Nil.
144	No	22	Female	not specified	Prednisolone, azothioprine.	Nil.
145	Yes	52	Female	not specified	Nil.	Nil.
146	Yes	33	Male	not specified	Nil.	Nil.
147	Yes	34	Female	distal colitis	Mesalazine.	Nil.
148	Yes	36	Male	not specified	Azothioprine, mesalazine.	Nil.
149	Yes	51	Female	not specified	Mesalazine.	Nil.
150	Yes	23	Female	proctitis	Azothioprine, mesalazine.	Nil.

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## APPENDIX 3

### PATIENT PROFILE (PSORIATIC ARTHRITIS)

### Appendix 3 Patient profile, Psoriatic arthritis

Patient No.	Age	Sex	Medication on recruitment to study.
151	53	Female	Methotrexate.
152	59	Male	Methotrexate, co-codamol.
153	42	Male	Methotrexate, naproxen.
154	23	Male	Voltarol, sulphasalazine.
155	40	Female	Naproxen, auranifin.
156	24	Female	Methotrexate.
157	35	Male	Sulphasalazine, diclofenic.
158	43	Female	Methotrexate, flexin.
159	63	Female	Methotrexate.
160	31	Female	IM Gold, voltarol.
161	40	Male	Methotrexate, co-dydramol.
162	71	Male	Diclofenic.
163	60	Female	Myocrisin, naproxen.
164	60	Female	Lodine, co-codamol.
165	51	Male	Methotrexate, dihydrocoedine.
166	45	Male	Sulphasalazine, diclofenic, E45.
167	36	Female	Methotrexate, naproxen, co-dydramol.
168	39	Male	Methotrexate, naproxen, co-codamol.
169	29	Female	Sulphasalazine.
170	26	Male	Sulphasalazine.
171	23	Male	Methotrexate.
172	73	Female	Methotrexate.
173	35	Male	Sulphasalazine.
174	55	Male	Sulphasalazine, co-codamol.
175	46	Male	Methotrexate, naproxen.

176	50	Female	Prednisolone.
177	33	Female	I M Gold.
178	43	Female	Methotrexate, co-proxamol.

APPENDIX 4  
INFORMATION SHEET

#### Appendix 4; Information sheet.

##### Quality of life in inflammatory bowel disease; Patient information sheet.

We are very much aware that inflammatory bowel disease (ulcerative colitis and Crohn's disease ) has considerable effects upon overall quality of life. We realise that in addition to the physical discomfort associated with abdominal pain and altered bowel function, your disease may have an impact upon your general well-being. Some patients feel that they perform less well at work because of their disease; have recreational difficulties, family stresses and anxiety or depression may occur.

The study that we are undertaking aims to carefully define the impact of inflammatory bowel disease upon the quality of your life. This will help us design ways of improving treatment regimes. To do this we will carefully assess the extent and severity of your disease by looking at your medical records, recording your current symptoms using diaries and ask you to complete questionnaires. We will also ask about any problems you have experienced at work or in recreation and will ask you to complete a simple questionnaire which addresses whether you have a tendency towards anxiety or depression.

In addition we want to find out whether regular counselling effects quality of life and disease severity. To do this we will randomly allocate you to one of two treatment regimes. Both regimes will involve standard medical therapy in the medical out-patients department. One group will receive additional counselling by the research nurse. Counselling will involve full discussions of any problems associated with your condition, appropriate management of any stresses and as much educational information about your condition as possible. counselling sessions will be repeated

at six monthly intervals. To find out whether counselling helps your overall well-being you will be asked to complete simple questionnaires at regular intervals.

Be fully assured that all information will be strictly confidential. Furthermore you are entitled to withdraw from the study at any stage and this will not affect your medical management in any way. Thank you for reading this sheet.

APPENDIX 5

CONSENT FORM



PATIENT CONSENT FORM

PATIENT NO.

INFLAMMATORY BOWEL DISEASE STUDY

PATIENT'S NAME: \_\_\_\_\_

RESEARCHER'S NAME: \_\_\_\_\_

I FREELY CONSENT TO PARTICIPATE IN THIS CLINICAL STUDY, THE NATURE OF WHICH HAS BEEN EXPLAINED TO ME BY THE ABOVE NAMED CLINICIAN.

I HAVE RECEIVED ,READ AND UNDERSTOOD THE "PATIENT INFORMATION SHEET" AND HAD ANY QUESTIONS I HAD RELATING TO THE STUDY ANSWERED TO MY SATISFACTION.

I AM WILLING TO COOPERATE WITH THE REQUIREMENTS OF THIS STUDY BUT RESERVE THE RIGHT TO WITHDRAW MY CONSENT AT ANY TIME WITHOUT REASON AND WITHOUT PREJUDICE TO MY FURTHER TREATMENT.

SIGNATURE OF PATIENT \_\_\_\_\_ DATE    /    /    .

I CONFIRM THAT THE ABOVE NAMED PATIENT HAS AGREED TO PARTICIPATE IN THIS STUDY, THE NATURE OF WHICH I HAVE EXPLAINED TO HIM /HER.

SIGNATURE OF RESEARCHER \_\_\_\_\_ DATE    /    /    .

APPENDIX 6

CDAI DIARY CARD



## APPENDIX 7

### HAD SCALE

## ASSESSMENT OF HOW YOU ARE FEELING

For each question please tick the answer which matches best how you feel

1) I feel tense or "wound up"

Most of the time.....  
A lot of the time.....  
Time to time, occasionally.....  
Not at all.....

2) I still enjoy the things I  
used to enjoy

Definitely as much.....  
Not quite as much.....  
Only a little.....  
Hardly at all.....

3) I get a sort of frightened feeling as  
if something awful is about to happen

Very definitely and quite badly.....  
Yes, but not too badly.....  
A little, but it doesn't worry me.....  
Not at all.....

4) I can laugh and see the funny  
side of things

As much as I always could.....  
Not quite so much now.....  
Definitely not so much now.....  
Not at all.....

5) Worrying things go through  
my mind

A great deal of the time.....  
A lot of the time.....  
From time to time but not  
too often.....  
Only occasionally.....

6) I feel cheerful

Not at all.....  
Not often.....  
Sometimes.....  
Most of the time.....

7) I can sit at ease and  
feel relaxed

Definitely.....  
Usually.....  
Not often.....  
Not at all.....

8) I feel as if I am slowed down

Nearly all the time.....  
Very often.....  
Sometimes.....  
Not at all.....

9) I get a sort of frightened feeling  
like butterflies in the stomach

Not at all.....  
Occasionally.....  
Quite often.....  
Very often.....

10) I have lost interest in  
my appearance

Definitely.....  
I don't take quite so much  
care as I should.....  
I may not take quite as much care  
I take just as much care as ever

11) I feel restless as if I have to be  
on the move

Very much indeed.....  
Quite a lot.....  
Not very much.....  
Not at all.....

12) I look forward with enjoyment  
to things

As much as ever I did.....  
Rather less than I used to.....  
Definitely less than I used to.....  
Hardly at all.....

13) I get sudden feelings of panic

Very often indeed.....  
Quite often.....  
Not very often.....  
Not at all.....

14) I can enjoy a good book or  
radio or TV programme

Often.....  
Sometimes.....  
Not often.....  
Very seldom.....

## APPENDIX 8

### SYTTLES AND STRATEGIES (CSQ) SCALE

## STYLES AND STRATEGIES

Name: \_\_\_\_\_

Age: \_\_\_\_\_

Sex: \_\_\_\_\_

**Instructions:** Although people may react in different ways to different situations, we all tend to have a characteristic way of dealing with things which upset us. How would you describe the way you typically react to stress? Circle **Always (A)**, **Often (O)**, **Sometimes (S)**, or **Never (N)** for **each** item below:

- |     |  |   |   |   |   |
|-----|--|---|---|---|---|
| 1.  | Feel overpowered and at the mercy of the situation.                                  | A | O | S | N |
| 2.  | Work out a plan for dealing with what has happened.                                  | A | O | S | N |
| 3.  | See the situation for what it actually is and nothing more.                          | A | O | S | N |
| 4.  | See the problem as something separate from myself so I can deal with it.             | A | O | S | N |
| 5.  | Become miserable or depressed.   | A | O | S | N |
| 6.  | Feel that no-one understands.  | A | O | S | N |
| 7.  | Do not see the problem or situation as a threat.                                     | A | O | S | N |
| 8.  | Feel that you are lonely or isolated.  | A | O | S | N |
| 9.  | Daydream about times in the past when things were better.                            | A | O | S | N |
| 10. | Take action to change things.  | A | O | S | N |
| 11. | Feel helpless - there's nothing you can do about it.                                 | A | O | S | N |
| 12. | Try to find out more information to help make a decision about things.               | A | O | S | N |
| 13. | Keep things to myself and not let others know how bad things are.                    | A | O | S | N |
| 14. | Think about how someone I respect would handle the situation and try to do the same. | A | O | S | N |
| 15. | Feel independent of the circumstances.   | A | O | S | N |
| 16. | Sit tight and hope it all goes away.   | A | O | S | N |
| 17. | Take my frustrations out on the people closest to me.                                | A | O | S | N |
| 18. | Resolve the issue by not becoming identified with it.                                | A | O | S | N |
| 19. | Respond neutrally to the problem.  | A | O | S | N |
| 20. | Pretend there's nothing the matter, even if people ask.                              | A | O | S | N |
| 21. | Get things into proportion - nothing is really that important.                       | A | O | S | N |

22.	Believe that time will somehow sort things out.	A	O	S	N
23.	Feel completely clear-headed about the whole thing.	A	O	S	N
24.	Try to keep a sense of humour - laugh at myself or the situation.	A	O	S	N
25.	Keep thinking it over in the hope that it will go away.	A	O	S	N
26.	Believe that I can cope with most things with the minimum of fuss.	A	O	S	N
27.	Try not to let my heart rule my head.	A	O	S	N
28.	Daydream about things getting better in future.	A	O	S	N
29.	Try to find a logical way of explaining the problem.	A	O	S	N
30.	Decide it's useless to get upset and just get on with things.	A	O	S	N
31.	Feel worthless and unimportant.	A	O	S	N
32.	Trust in fate - that things will somehow work out for the best.	A	O	S	N
33.	Use my past experience to try to deal with the situation.	A	O	S	N
34.	Try to forget the whole thing has happened.	A	O	S	N
35.	Just take nothing personally.	A	O	S	N
36.	Become irritable or angry.	A	O	S	N
37.	Just give the situation my full attention.	A	O	S	N
38.	Just take one step at a time.	A	O	S	N
39.	Criticise or blame myself.	A	O	S	N
40.	Pray that things will just change.	A	O	S	N
41.	Think or talk about the problem as if it did not belong to me.	A	O	S	N
42.	Talk about it as little as possible.	A	O	S	N
43.	Prepare myself for the worst possible outcome.	A	O	S	N
44.	Look for sympathy from people.	A	O	S	N
45.	See the thing as a challenge that must be met.	A	O	S	N
46.	Be realistic in my approach to the situation.	A	O	S	N
47.	Think about something else.	A	O	S	N
48.	Do something to make me feel better.	A	O	S	N



## APPENDIX 9

### ATTITUDES AND PREFERENCES (ECQ) SCALE

## ATTITUDES AND PREFERENCES

Name :

Sex :

Age :

Instructions : Please indicate how you feel about each item by circling either "TRUE" or "FALSE". If you feel that an item is neither entirely true nor false, please choose the alternative that is most like you. If you haven't been in the situation described, please say how you feel you would behave in that situation.

- |  |            |
|--|------------|
| 1. When someone upsets me, I try to hide my feelings.  | TRUE FALSE |
| 2. I remember things that upset me or make me angry for a long time afterwards.  | TRUE FALSE |
| 3. People find it difficult to tell whether I'm excited about something or not.  | TRUE FALSE |
| 4. I find it difficult to comfort people who have been upset.  | TRUE FALSE |
| 5. I generally don't bear a grudge - when something is over, it's over, and I don't think about it again.                        | TRUE FALSE |
| 6. When something upsets me I prefer to talk to someone about it than to bottle it up.   | TRUE FALSE |
| 7. I get "worked up" just thinking about things that have upset me in the past.  | TRUE FALSE |
| 8. If I receive bad news in front of others I usually try to hide how I feel.  | TRUE FALSE |
| 9. I seldom show how I feel about things.  | TRUE FALSE |
| 10. I often find myself thinking over and over about things that have made me angry.   | TRUE FALSE |
| 11. If I'm pleasantly surprised, I show immediately how pleased I am.  | TRUE FALSE |
| 12. If I get angry or upset I usually say how I feel.  | TRUE FALSE |
| 13. I can usually settle things quickly and be friendly again after an argument.   | TRUE FALSE |
| 14. I don't feel embarrassed about expressing my feelings.   | TRUE FALSE |
| 15. If I see or hear about an accident, I find myself thinking about something similar happening to me or to people close to me. | TRUE FALSE |
| 16. I think about ways of getting back at people who made me angry long after the event has happened.                            | TRUE FALSE |
| 17. I never forget people making me angry or upset, even about small things.   | TRUE FALSE |
| 18. I think people show their feelings too easily.   | TRUE FALSE |

19. I find it hard to get thoughts about things that have upset me out of my mind. TRUE FALSE
20. I often daydream about situations where I'm getting my own back at people. TRUE FALSE
21. Expressing my feelings makes me feel very vulnerable and anxious. TRUE FALSE
22. If I see something that frightens or upsets me, the image of it stays in my mind for a long time afterwards. TRUE FALSE
23. Thinking about upsetting things just seems to keep them going, so I try to put them out of my mind. TRUE FALSE
24. I usually manage to remain outwardly calm, even though I may be churned up inside. TRUE FALSE
25. If I lose out on something, I get over it quickly. TRUE FALSE
26. I can't help showing how I feel, even when it isn't appropriate to do so. TRUE FALSE
27. If I have to confront someone, I try not to think too much about it beforehand. TRUE FALSE
28. Sometimes I just can't control my feelings. TRUE FALSE
29. Instructions which are precise and detailed usually oversimplify the problem. TRUE FALSE
30. In this society, whether you achieve anything is in the hands of people in power. TRUE FALSE
31. What happens in my life depends on my own actions. TRUE FALSE
32. The worst thing about managing is having to take other peoples' opinions into account. TRUE FALSE
33. Chance plays a role in most things that happen to people. TRUE FALSE
34. Joint decisions are usually better than individual ones. TRUE FALSE
35. I don't think ordinary people have much control over political events. TRUE FALSE
36. It's pointless planning too far ahead because too many things happen by chance. TRUE FALSE
37. I prefer to have everything ordered and in place, both at work and in my personal life. TRUE FALSE
38. I find it easy to fall into routines. TRUE FALSE
39. If bad luck is on the way, there's not much you can do to avoid it. TRUE FALSE
40. When I'm in charge, I want my instructions followed to the letter. TRUE FALSE
41. How well you do in examinations depends as much on the examiner's mood as on your ability. TRUE FALSE

42. When I'm trying to get a job done, there's always someone who tries to upset the apple-cart. TRUE FALSE
43. I'm usually able to achieve the goals I set myself. TRUE FALSE
44. I think a diplomatic and accommodating style of leadership gets more done than a dominant and forceful one. TRUE FALSE
45. The worthwhile things in life are obtained by hard work. TRUE FALSE
46. Some people's abilities just aren't recognized, no matter how hard they try. TRUE FALSE
47. I've always tried to have my life and my career clearly mapped out. TRUE FALSE
48. I don't believe in luck. TRUE FALSE
49. You can't be too concerned about what others think when you're trying to get things done. TRUE FALSE
50. I tend to believe that "what will be, will be". TRUE FALSE
51. Compared to my friends and colleagues, I find vague or ambiguous situations easy to tolerate. TRUE FALSE
52. I thrive on hectic, high-pressure work. TRUE FALSE
53. I enjoy work, but I always make sure I have plenty of time with family and friends. TRUE FALSE
54. I tend to talk much faster than most other people I know. TRUE FALSE
55. I'm always in a rush, even when I don't have to be. TRUE FALSE
56. I have very high standards, and I expect others to meet them. TRUE FALSE
57. A game is never just a game for me - I always play to win. TRUE FALSE
58. When I eat, I like to take my time and enjoy it - I hate snatching a bite on the run. TRUE FALSE
59. When people speak slowly, I find myself getting irritated and wanting to speak for them. TRUE FALSE
60. When I leave work, I drop all the problems of the day until tomorrow. TRUE FALSE
61. I hate having to try to do more than one thing at a time. TRUE FALSE
62. Waiting makes me nervous and fidgety. TRUE FALSE
63. When I'm doing something I've done before, I try to do it faster than the last time. TRUE FALSE
64. I never lose sleep trying to plan what I'm going to do the next day. TRUE FALSE

## APPENDIX 10

### SF 36 QUESTIONNAIRE

# ASSESSMENT OF OVERALL HEALTH STATE (SF36)

1) In general would you say your health is: (Tick one box)

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2) Compared to one year ago, how would you rate your health in general now? (Tick one box)

Much better than 1 year ago	<input type="checkbox"/>
Somewhat better now than 1 year ago	<input type="checkbox"/>
About the same as 1 year ago	<input type="checkbox"/>
Somewhat worse than 1 year ago	<input type="checkbox"/>
Much worse than 1 year ago	<input type="checkbox"/>

3) The following items are about activities you, might do during a typical day. Does your health limit you in these activities? If so how much? (Tick one box on each line)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Moderate activities, such as moving a table, pushing a vacuum cleaner, or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Climbing one flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) bending, kneeling or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Walking more than a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Walking more than half a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Walking one hundred yards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4) During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health?

	yes	no
a) Cut down the amount of time you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>
b) Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>
c) Were limited in the kind of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>
d) Had difficulty performing the work or other activities ( for example it took extra effort)	<input type="checkbox"/>	<input type="checkbox"/>

5) During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)

a) Cut down the amount of time you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>
b) Accomplished less than you would like	<input type="checkbox"/>	<input type="checkbox"/>
c) Didn't do work or other activities as carefully as usual	<input type="checkbox"/>	<input type="checkbox"/>

6) During the past 4 weeks, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7) How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9) How much time during the past 4 weeks.....

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a) Did you feel full of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Have you been a very nervous person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Have you been so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Have you felt downhearted and blue?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Did you feel worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Have you been a happy person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Did you feel tired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Has your health limited your social activities (like visiting with friends or close relatives)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10) During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11) Please choose the answer that best describes how TRUE or FALSE each of the statements is for you.

	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
a) I seem to get sick a little easier than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I am as healthy as anybody I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) My health is excellent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



APPENDIX 11

LIFE EVENTS SCALE

## LIFE EVENTS

We constantly experience events which may either have a **Positive** or **Negative** on us.

For example, we may start a new relationship which we will probably rate as a positive event.

On the other hand, a relationship may end and in this case we may rate it positively if we wanted it to end but negatively if we didn't.

Another example might be failing an examination, or more seriously, a death in the family both of which will normally be regarded as negative or stressful events.

Please circle on the chart below the number of **Positive** or **Negative** events (ignore events which were more or less neutral) which you can remember happening to you **over the past four weeks**.

Number of negative or stressful events over the past four weeks.

1      2      3      4      5      6      7      8      9      10

Number of positive events over the past four weeks.

1      2      3      4      5      6      7      8      9      10

APPENDIX 12  
CORRELATION MATRIX  
(CROHN'S DISEASE)

Appendix 12 Correlation matrix Crohn's disease (n=50)

	Had anx	Had dep	AP r	AP em	AP loc	AP tamb	AP type	SS det	SS rat	SS em	SS av	Sf pf	Sf sf	Sf rp	Sf ef	Sf mh	Sf ene	Sf pain	Sf ghp	Sf cha	CDAI	Dis
Haddep	0.45																					
AP r	0.19	-0.12																				
AP em	-0.11	0.11	0.10																			
AP loc	0.20	-0.05	0.56	0.11																		
AP tamb	0.02	0.06	0.20	0.11	0.42																	
AP type	0.18	0.01	-0.02	0.17	0.43	0.36																
SS det	-0.21	-0.19	0.04	0.22	-0.04	0.05	0.08															
SS rat	-0.10	-0.03	-0.03	0.04	-0.17	0.02	-0.08	0.77														
SS em	0.36	-0.07	0.16	-0.15	0.38	0.10	0.28	-0.15	-0.44													
SS av	0.31	-0.05	0.14	0.19	0.28	0.20	0.15	-0.14	-0.46	0.58												
Sf pf	0.06	0.23	0.06	0.03	0.01	0.40	0.14	0.07	0.09	0.04	0.03											
Sf sf	0.21	0.08	0.46	0.07	0.49	0.13	0.04	-0.03	0.19	0.08	0.05	0.09										
Sf rp	-0.15	-0.42	0.04	-0.42	0.07	-0.17	0.07	0.14	0.12	0.15	0.16	-0.53	-0.06									
Sf ef	-0.20	-0.29	0.11	-0.29	-0.13	-0.32	-0.21	0.26	0.10	-0.02	-0.19	-0.16	-0.17	0.37								
Sf mh	-0.05	-0.39	0.17	-0.38	0.22	0.13	0.24	-0.18	-0.08	-0.03	-0.02	-0.08	0.05	0.04	-0.11							
Sf ene	-0.35	-0.56	0.13	-0.56	0.25	0.05	0.13	0.19	0.18	-0.09	-0.03	-0.20	0.12	0.23	0.17	0.72						
Sf pain	-0.48	-0.49	0.03	-0.48	0.03	0.09	-0.09	0.03	-0.02	0.03	-0.10	0.01	-0.23	0.67	0.40	0.07	0.33					
Sf ghp	0.03	-0.16	0.16	-0.15	0.19	0.07	0.07	0.03	-0.04	-0.15	-0.10	0.11	0.11	0.31	0.04	-0.13	-0.08	0.20				
Sf cha	-0.18	-0.46	0.18	-0.46	0.12	0.12	0.12	0.08	-0.03	-0.17	-0.03	-0.48	-0.20	0.56	0.26	0.20	0.31	0.52	0.32			
CDAI	0.32	0.37	0.09	0.38	0.04	0.20	-0.20	-0.18	0.03	-0.04	-0.31	0.35	0.16	-0.60	-0.11	0.11	-0.08	-0.61	-0.28	-0.39		
Dis	0.16	0.56	-0.01	0.56	-0.05	-0.01	-0.01	-0.16	0.06	-0.23	-0.17	0.48	0.22	-0.56	-0.20	-0.01	-0.10	-0.59	-0.27	-0.46	0.52	
Info	0.02	0.19	0.09	0.19	0.03	0.06	0.06	-0.04	-0.23	0.22	0.13	0.04	-0.14	-0.15	-0.05	-0.03	-0.04	-0.04	-0.26	-0.07	0.17	0.38

positive and negative life events have been excluded from correlation matrix.

Key to matrix: Hadanx = HAD anxiety score, Haddep = HAD depression score, AR r = Attitudes and Preferences Rehearsal score, AP em = Attitudes and Preferences Emotional score, AP loc = Attitudes and Preferences locus of control score, AP tamb = Attitudes and Preferences tolerance for ambiguity, AP types = Attitudes and Preferences type A personality, SS det = Styles and Strategies detached score, SS rat = Styles and Strategies rational score, SS em = Styles and Strategies emotional score, SS av = Styles and Strategies avoidance score, Sf pf = SF36 physical function, Sf sf = SF36 social function, Sf rp = SF36 role physical, Sf ef = SF36 emotional function, Sfmh = SF36 mental health, Sf ene = SF36 energy/fatigue, Sf pain = SF36 pain, Sf ghp = SF36 general health perception, Sf cha = SF 36 change in health, CDAI = Crohn's disease activity index, Dis = Disease specific questionnaire, Info = Information provision factor of disease specific questionnaire.

## APPENDIX 13

### CORRELATION MATRIX (ULCERATIVE COLITIS)

Appendix 13 Correlation matrix ; Ulcerative colitis (n=50)

	Had aux	Had dep	AP r	AP em	AP loc	AP tamb	AP type	SS det	SS rat	SS em	SS av	SF pf	SF sf	SF rp	SF ef	SF mh	SF ene	SF pain	SF ghp	SF cha	SF Dis	Cdai	Dis
Haddep	0.46																						
AP r	0.33	0.10																					
AP em	0.19	0.36	0.20																				
AP loc	0.07	-0.06	0.40	-0.06																			
AP tamb	0.40	0.11	0.31	0.31	0.32																		
AP type	0.05	-0.06	0.13	0.14	0.15	0.29																	
SS det	-0.31	-0.44	-0.18	-0.17	0.16	0.05	-0.11																
SS rat	-0.21	-0.28	-0.07	-0.06	-0.07	0.03	-0.07	0.73															
SS em	-0.65	0.25	0.35	0.06	0.24	0.32	0.19	-0.42	-0.30														
SS av	0.19	0.05	0.33	0.15	0.27	0.18	0.32	-0.05	-0.21	0.42													
SF pf	0.01	0.35	-0.02	0.13	-0.13	0.02	-0.07	-0.09	0.04	-0.01	-0.29												
SF sf	0.06	-0.07	0.03	0.01	0.28	0.25	0.19	0.21	0.29	-0.01	-0.12	0.07											
SF rp	-0.31	-0.40	0.10	-0.11	0.11	-0.13	0.07	0.12	0.09	-0.11	0.08	-0.61	-0.22										
SF ef	-0.38	-0.25	-0.01	-0.14	0.23	-0.13	0.13	0.13	-0.11	-0.22	0.15	-0.50	-0.24	0.56									
SF mh	0.24	0.01	0.05	-0.13	0.16	0.16	0.07	-0.24	-0.18	0.31	-0.07	-0.01	0.09	-0.11	0.06								
SF ene	-0.22	-0.33	-0.07	-0.27	0.21	0.04	0.17	0.12	-0.02	-0.04	0.01	-0.33	0.06	0.28	0.54	0.73							
SF pain	-0.20	-0.36	-0.01	-0.01	-0.07	-0.14	0.01	0.15	0.03	-0.19	-0.04	-0.65	-0.08	0.60	0.44	-0.32	-0.01						
SF ghp	-0.27	-0.17	0.09	-0.30	-0.03	-0.23	-0.19	0.11	-0.10	-0.17	0.02	-0.23	0.01	0.23	0.32	0.28	0.24	0.24					
SF cha	0.09	-0.14	-0.02	-0.03	0.14	0.02	0.20	0.15	0.16	0.02	-0.01	-0.28	0.21	0.24	0.20	0.10	0.16	0.37	0.04				
CDAI	0.42	0.13	0.03	0.13	0.06	0.26	0.13	-0.02	-0.06	0.45	0.16	0.16	0.07	-0.31	-0.35	0.13	-0.13	-0.26	-0.10	0.10			
Dis	0.31	0.43	0.01	0.06	0.02	0.09	-0.09	-0.24	-0.15	0.30	-0.02	0.32	-0.14	-0.35	-0.25	0.25	-0.04	-0.50	-0.12	-0.29	0.30		
Info	0.11	-0.03	0.26	0.05	0.06	-0.20	-0.12	-0.28	-0.12	0.30	-0.01	0.27	-0.34	-0.02	-0.01	0.14	-0.02	-0.14	-0.24	0.01	-0.08	0.02	

positive and negative life events have been excluded from correlation matrix.

Key to matrix: Hadanx = HAD anxiety score, Haddep = HAD depression score, AR r = Attitudes and Preferences Rehearsal score, AP em = Attitudes and Preferences Emotional score, AP loc = Attitudes and Preferences locus of control score, AP tamb = Attitudes and Preferences tolerance for ambiguity, AP types = Attitudes and Preferences type A personality, SS det = Styles and Strategies detached score, SS rat = Styles and Strategies rational score, SS em = Styles and Strategies emotional score, SS av = Styles and Strategies avoidance score, SF pf = SF36 physical function, SF sf = SF36 social function, SF rp = SF36 role physical, SF ef = SF36 emotional function, Sfmh = SF36 mental health, SF ene = SF36 energy/fatigue, SF pain = SF36 pain, SF ghp = SF36 general health perception, SF cha = SF 36 change in health, CDAI = Crohn's disease activity index, Dis = Disease specific questionnaire, Info = Information provision factor of disease specific questionnaire.